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The Journey from Dementia Diagnosis to Final Bereavement: An Exploration of the Fluctuating Perceptions of Self Experienced by Family Caregivers of People with Dementia

Eva Joanna Alexjuk

Thesis presented in fulfilment of the requirement

of the degree of Doctor of Philosophy

University of Edinburgh - 2018

Declaration

This is to certify that that the work contained within has been composed by me and is entirely my own work. No part of this thesis has been submitted for any other degree or professional qualification.

Eva Joanna Alexjuk

Dated:

Abstract of Thesis

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Title of thesis:	The Journey from Dementia Diagnosis to Final Bereavement: An Exploration of the Fluctuating Perceptions of Self Experienced by Family Caregivers of People with Dementia		

Insert the abstract text here - the space will expand as you type.

Few research studies have examined the panoramic landscape of family caregivers from dementia diagnosis to the final bereavement of the person with dementia for whom they are caring. The routes and pathways of care undertaken during a caregiver's journey will be individual to each person, yet invariably there will be some similarities as to how they anticipate, approach and manage this journey. From the caregiver's perspective, caring for someone with dementia is related to more than the cognitive loss experienced by their family member, there are many losses involved. This research study aims to explore the complex emotional experiences of thirty caregivers in relation to sense of self, change, grief, loss and bereavement, to elucidate a deeper understanding of the lived experience, the perceived and understood reality of the experiential journey of caregivers. To explore the experiences of caregiving, this research study uses a hermeneutic phenomenological approach and draws on an adaptation of the theoretical framework of anticipatory grief and loss by Fulton and Fulton (1971) and Fulton and Gottesman (1980). The study uses a convenience sample and semi structured interview format and involves two non-comparative participant groups of family caregivers living in urban and rural communities within the North East of England. Group one comprises of twenty bereaved participants, nineteen of whom are spousal caregivers and one adult-caregiving daughter, who were interviewed once to explicate a retrospective perspective of the caring experience. Group two comprises of ten participants, nine spousal caregivers and one adult-caregiving daughter, who are currently caring for a family member living with an advanced stage experience of dementia. Group two participants were interviewed on three occasions across an eighteen-month time period to explore the retrospective and prospective experience of their caregiving role.

The analysis of data reveals expressions of change, grief and loss within a complex and tri-dimensional landscape. Within this landscape, participants highlight defined periods of their journey, particularly with regard to their experience of a protracted middle period, which they referred to as being "*the long road*". However, intersecting with this layered landscape, the analysis of data also reveals a key aspect of caregiving - the emergence of a conceptual framework involving three interconnected yet fluctuating schemas of self experienced by participants. The first schema, the individual '*me-self*', relates to the participant's perception of their core self and envisaged sense of self. The second schema, the '*relationship-self*', illustrates participant's physical and psychological experiences and bonded connection between themselves and the cared-for spousal partner or parent, as well as other family members and care workers. The third schema, the '*caregiving-self*', is associated with the acquisition and undertaking of their role of familial caregiver. The findings of this study highlight the '*lived-world*' experience of family caregivers as being a journey which subjects them to a cyclical maelstrom of emotion and fluctuating perception of their schemas of self.

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This research study aims to explore the complex emotional experiences of thirty dementia caregivers in relation to sense of self, change, grief, loss and bereavement, to elucidate a deeper understanding of the lived experience, the perceived and understood reality of the experiential journey. The study uses a convenience sample and semi structured interview format, involving two non-comparative participant groups of family caregivers living in urban and rural communities within the North East of England. Group one comprises of twenty bereaved participants, nineteen of whom are spousal caregivers and one adult-caregiving daughter, who were interviewed once to explicate a retrospective perspective of their caring experience. Group two comprises of ten bereaved participants, nine spousal caregivers and one adult-caregiving daughter, who are currently caring for a family member living with an advanced stage experience of dementia. Group two participants were interviewed on three occasions across an eighteen-month time period to explore the retrospective and prospective experience of their caregiving role. The findings of this study highlight the *'lived-world'* experience of family caregivers as being a journey which subjects them to a cyclical maelstrom of emotion and fluctuating perception of their schemas of self.

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Like a Leaf

A Poem in Memory of Vasili Jacovitch Oleksuik[1] Who Died on 31st October 2010

Like a leaf blown by the wind

You came

Displaced from your roots

The seeds of a new life sown

Far from the land you once knew

You laboured long days of toil and sweat

Black coal dust covered your body

Green fingers held prize-winning chrysanthemums

Yet memories of the past tormented your present

The clarity of a life clouded by anger

Time passed

Resentment dissolved into sadness

Mourning the loss of your child and the man you once were

Your physical strength sapped and your thoughts scattered

Like the leaves on the lawn on Halloween

(Eva Joanna Alexjuk, 2013)

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[1] In 1947 '*Vasil*', my step-father and the man I regarded as being "*my dad*" for 36 years came to the UK as a Ukrainian refugee. On entry to the UK he was categorised as a "*displaced person*" and his family name was anglicised by the authorities to that of Alexjuk. Much to his anger and consternation he was persistently referred to, by people within the wider community in which we live, as simply being "*Basil the Pole*". Unable to return to his native homeland, he always felt that he was denied his identity and that his true sense of self was lost within a foreign landscape into which he was consistently trying to assimilate.

Acknowledgements

As with all journeys, this PhD research journey had a beginning, middle and finally, an end. Now, looking back, it appears to have been a long and eventful experience, involving many people who have contributed to and supported me throughout my journey.

Firstly, I would like to offer a special thanks to members of staff of the Alzheimer's Society in the North East region of England, who initially introduced me to the family caregivers who agreed to be interviewed as part in this research study. I would like to offer a very special "*thank you*" to all of the participants for making me feel so welcome and for sharing their experiences of caring for their family member with dementia. I now have memories of our conversations, often filled with laughter and sometimes with tears, as well as numerous cups of tea. It was such a pleasure to have met and worked with you all.

I am deeply grateful for the wonderful guidance given to me over many years by my supervisors Prof. Charlotte Clarke, Dr. Catherine Gibb and more recently, by Prof. Heather Wilkinson. Thank you for your patience and support, especially in talking me through my periods of self-doubt.

I would also like to offer my thanks to my former colleagues, people living with dementia and volunteers involved with Alzheimer's Society, who I believe assisted in formulating the foundations of my understanding of dementia care. Thank you to Prof. Julian Hughes, Dr. Lynn Corner, Dr. Amit Dias and my MSc in Dementia supervisor Dr. Louise McCabe, for encouraging me to commence my PhD research.

For their technical support, I would like to say a big thank you to Dr. Phil Hodgson, Jenni Benyon and Garry Storer. I would also like offer my thanks to my friends and wonderful colleagues: Dr. Veronica Adamson; Dr. Sarah Keyes; Dr. Jessie Paterson; Dr. Pam Ramsey; Dr. Marion Smith; Dr. Liz Taylor; Dr. Julie Watson and Dr. Jane Wilcockson, for listening to me when I simply wanted to talk about my research.

I wish to offer a special thank you to my friends Molly Herridge, Kiran Haskar and Gwen Marples, for always being there when I needed them. I would also like to acknowledge my mother

Maureen Alexjuk and my mother-in-law Sheila Dixon, for periodically asking the question "*have you not finished it yet?"* This spurred me on to actually complete this research study and thesis.

Finally, I wish to thank Rob, my partner, for being my constant companion, especially during our emotionally challenging experiences of the last several years. I could not have done this without you my love.

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Overview of Thesis

> For many patients and their families the illness journey is a new experience, through uncharted territory – there is no A-Z or road atlas (Doherty et al., 2009: 503).

The quotation offered by Doherty and colleagues is perhaps a concise representation of the "*journey*" and experiential reality of family members caring for a relative with dementia. It is a journey which is unpredictable and often extending over a protracted period of time (Gillies, 2009). There is no turning back from this journey (Robinson et al., 2009), during which caregivers traverse paths and detours of change, ambiguity and experiential loss (Boss, 2004; Fetherstonhaugh et al., 2017; Gillies, A., 2009; Gillies, B., 2012). It is often experienced as *a "journey into the unknown"* (Davis, 2011: 217).

Chapter One: The Research Journey

Within this introductory chapter, I offer a brief mise-en-scène description of the dementia caregiving landscape in the UK, as well as outling my work-based practice experience and the reasons why I have chosen this specific topic of research. In addition I have also defined the aim of my study and the application of terminology in describing the experiences of study participants.

Chapter Two: The Landscape of Dementia Care

This chapter offers a summary of the sourcing, review and synthesis of academic literature across the panoramic landscape of caregiving, grief, loss and bereavement, as well as relevant dementia-specific literature in relation to these experiential concepts. I begin by offering a broad discussion relating to UK dementia care policy development. In addition I review the expansion of care undertaken within the community and the subsequent development and acknowledgement of the role of family caregivers. I also discuss the differential experiences of caregiving undertaken by spousal partners and adult-caregiving children. Narrowing this conversation further, I explore the theoretical concepts of *'being'*, *'self'* and *'attachment'*, as well as the epistemological concepts and ontological understanding of the complexities of change, grief, loss and bereavement.

Chapter Three: The Methodological Approach to the Research Journey

The third chapter of this document offers my anticipatory views of undertaking this journey and a repetition of the aim of this research study. I then progress to discuss the methodological routes I initially considered and my reasons for finally choosing a hermeneutic phenomenological approach. Within this chapter I describe the overall design of this study, in essence the '*mapping out'* of this research journey, including the recruitment of thirty family caregivers living within the North East region of England. In addition a brief introductory synopsis of each person is also given. The coding and analysis of data is also discussed, as well as the application and adaptation of the theoretical framework of anticipatory grief and loss by Fulton and Fulton, (1971) and, Fulton and Gottesman, (1980) across the entire caregiving journey. The adapted framework is interpreted and presented as a tri-dimensional landscape relating to participants' experiences to change during their caregiving journey. Intersecting with this layered landscape I also present the analysis of data relating to the emergence of a conceptual framework involving three interconnected, yet fluctuating schemas of self experienced by study participants. This chapter also includes a reflective and reflexive view relating to the location and orientation of myself within the landscape during the course of this research study.

Chapter Four: Fluctuating Perceptions of Self within the Landscape of Dementia Care

The findings of this research study are presented as a hermeneutic phenomenological interpretation of the essential features of the fluctuating perceptions self experienced by participants within a tri-dimensional landscape. Themes relating to participants' fluctuating schemas of self are presented and discussed using quotations taken from interview transcriptions, which highlight participants' experiences and expressions of emotions relating to change, grief, loss and bereavement during the course of the their dementia caregiving journey.

Chapter Five: Self and Being within the Dementia Care Landscape

This chapter examines the essence of this study in the experience of dementia caregiving, focussing on the emergence of the conceptual framework relating to the fluctuating perceptions of self of family caregivers involved with this research study. In doing so, it attempts to understand the

similar and differential experiences of sense of self, change, grief, loss and bereavement vis-à-vis to reported findings in current literature appertaining to familial dementia caregivers.

Chapter Six: Looking Back and Looking Forward

In the final chapter of this document I highlight the contribution to existing knowledge with regard to the retrospective and prospective experiences of family caregivers and the emergence of the concept relating to the fluctuating perceptions of self. I also review the methodological route undertaken in answering the aim of this research study research. My own positioning within the dementia care landscape is also reflectively discussed. In addition, the limitations of this study and disseminations of findings, as well as implications for practice, recommendations and suggestions for future research are also reviewed. Finally, I offer my reflection of the journey undertaken within the context of this study.

Chapter One

The Research Journey

1.0 Introduction

The first part of this chapter offers a brief description of the dementia caregiving landscape in the UK, as well as outlining my work-based experience and the reasons why I have chosen this specific topic of research. Within this chapter I have also outlined the aim of my study and the application of terminology in describing the experiences of the study participants.

Researchers such as Chan et al., (2012); Ducharme et al., (2012); Gillies, (2011); Shanley, (2006); Sutcliffe, et al., (2016) argue that it is imperative that given the complexity of the dementia caregiving role, together with the lack of appropriate information and support, necessitates further exploration and understanding of this issue. There has been a growing development of research which has explored the various facets of caregiving in relation to the psychological experiences of caregivers (Adams et al., 2008; Boss, 2006; Brodaty and Donkin, 2009; Brodaty et al., 2005; Brodaty and Green, 2002). Negative aspects, such as the burden of care experienced by family caregivers, have been addressed by researchers such as Chappell and Reid, (2002); DiBartolo, (2000); Dowling et al., (2014); Netto, Jenny and Yap, (2009). Conversely, studies relating to the positive characteristics of caregiving have also been explored (Lloyd, Patterson and Muer, 2016; Miesen, 2010; Netto, Jenny and Yap, 2009; Nolan, et al., 2003). More recently, the issues relating to the experiences of continuity and loss during the caregiving journey have also been undertaken by researchers such as Ducharme et al., (2013); Gillies, B., (2011); Peacock, Hammond-Collins and Forbes, (2014), and from an auto-biographical perspective by family caregivers such as Andrea Gillies, (2009) and Elizabeth Forsythe (1990).

However, there is to date a paucity of knowledge and understanding of experiential loss and grief of family caregivers (Blandin and Pepin (2015; Kjällman et al., 2013), even less with regard to these aspects across the entire dementia caregiving landscape (Peacock, Hammond-Collins and Forbes, 2014). In their paper relating to existential loss and wellbeing of dementia caregivers, particularly the experiences of spousal caregiving dyads, Piiparien and Whitlatch (2011) argue that

if researchers "*begin with the certainty that nothing is for certain", then we may be able to "work our way back"* (ibid: 198) in our examination of how this uncertainty forms the behaviour, thoughts and feelings of the family caregiver during their caregiving experience.

1.1 The Dementia Care Landscape

From a global perspective, Alzheimer's Disease International (ADI) highlight that currently there are 46.8 million people with dementia worldwide. Yet, it is estimated that by 2030 this number will reach 74.7 million and will almost double to 131.5 million by 2050 (ADI, 2015). The Alzheimer's Society reports that in the UK there are 850,000 people with dementia, of which two thirds are women. One in six people aged eighty years of age and over have some form of dementia (2015). Whilst the estimated number of people below the age of sixty five years experiencing early onset dementia is thought to be 40,000. Approximately, there are 25,000 people with dementia who are from black and minority ethnic (BME) groups. Within the next three decades, it is predicted that in total the number of people with dementia living in England, Wales and Northern Ireland is expected to rise to two million by 2050. Pertinent to this study, the number of people with dementia in the North East region of England is estimated to be 34,289.

With regard to mortality, a total of 60,000 deaths a year are directly attributable to dementia in England, Wales and Northern Ireland. However, delaying the onset of dementia by five years would reduce deaths directly related to dementia by 30,000 a year (Alzheimer's Society, 2015). In terms of economic expenditure, the cost of dementia to the UK as a whole is assessed as being £26 billion per annum, yet there are 670,000 family caregivers of people with dementia in the UK who contribute to financial savings of £11 billion a year (Alzheimer's Society, 2014).

The term dementia is used to describe a syndrome, a set of medical signs and symptoms, the causal factors of which relate to a number of illnesses, with Alzheimer's disease being the most prevalent form (Department of Health, (DH), 2009; Hughes, 2011). It is thought that many factors, including age, genetic background, medical history and lifestyle can combine to lead to the onset of dementia (Hughes, 2011; Hughes, Louw and Sabat (2006). The median life-expectancy for people experiencing dementia, particularly Alzheimer's disease, is thought to be around eight years from the point of diagnosis. However, it is estimated that one-third of patients aged between seventy five

and eighty four years of age, with a mini mental state examination (MMSE) score of between nineteen and twenty three, will die within a year. Nevertheless, people can live for as long as ten to fifteen years following diagnosis prior to their final physiological death (van der Steen et al., 2014; van der Steen et al., 2016). This means that the journey from diagnosis to death can be protracted as the trajectory of the illness can, more often than not, be several years before the terminal phase of dementia is reached (Hughes, 2011; van der Steen et al., 2016).

However, Hughes, Louw and Sabat (2006) argue that people often apply their initial understanding of dementia from a medicalised viewpoint. Nevertheless, they further comment on the occurrence of pathological change as being insufficient in highlighting:

> At the most objective end of "*mental illness*" (that is, in the field of "*organic*" dementias), there is no hard scientific boundary between disease and normality (ibid: 2).

For many caregivers, caring for a family member with dementia has been defined as an unrelenting task (Ducharme, Couture and Lamontagne, 2012; Ducharme, et al, 2011; Robinson, et al., (2009); Schulz and Sherwood, (2008). Often placing the caregiver at high risk of developing psychological symptoms of anxiety and depression (Cooper et al., 2008; Schulz and Martire, 2004) and vulnerable to experiencing other significant medical problems (Schulz and Sherwood, 2008). Currently there is no cure for any form of dementia (Peel and Harding, 2014).

1.2 Why this Particular Research Journey?

I began my career within the field of dementia care in 1997 as a supervisor working volunteers within a large branch of the Alzheimer's Society in the North East of England. From the very beginning of commencing my role I soon realised that the central tenet of my working relationship with family caregivers related to their approach in anticipating and managing their experiences of change and loss.

In addition to commencing my employment with the Alzheimer's Society, I also became involved with the charitable organisation Cruse Bereavement Care. The branch of Cruse with which I was involved covered a large geographical conurbation in the North East of England. My association

with this organisation, undertaken on a voluntary basis in the evenings and at weekends, began in 1998 and lasted for nine years.

Parallel to my work with this organisation, my day time role with the Alzheimer's Society developed into dementia care training for healthcare workers employed at local and national level from the health, statutory and voluntary sectors. Therefore, I was profoundly aware that this research study, this journey, was not going to take me into unchartered territory in relation to experiential change and loss, particularly with regard to dementia care. Given my chosen career path with the Alzheimer's Society, my long association with Cruse Bereavement Care and in recent years my academic work, the emotive issues relating to undertaking this research journey were firmly embedded in a familiar and at times intensely complex and ambiguous landscape. In undertaking this study, I initially perceived that I was not going to be a stranger in this landscape.

The remit in carrying out my various roles with the Alzheimer's Society meant that vicariously, whilst maintaining a professional distance, I had shared many journeys with family caregivers. Journeys although unique to the individual themselves, but which were often reported as being prodigiously similar in their duration and course. Caregivers cited events, stages and periods of their caregiving journey which were overwhelmingly memorable, sometimes wonderfully joyful and at other times deeply saddening. Frequently my day-to-day role was that of advocate, speaking on behalf of family caregivers who were either husbands, wives, children, nephews, nieces and family friends. For the majority of cases, I acted as an information gatekeeper, guiding caregivers through the contours of care and onto pathways, where possible, to additional social and health care services provided by other agencies within the locality. Yet more often than not, I was the person who just listened when they simply wanted to talk to someone about the practicalities of their caregiving role. I was their *"confidante in care",* at the beginning, during and finally at the point of their bereavement; in some cases even beyond.

In the first five years of working for the Alzheimer's Society I believed that as a branch my colleagues and I provided support to people living with dementia, such as awareness raising, consultation involvement, information guidance, advocacy support, day-care and weekend services. However, due to grant funding and project constraints I felt that what we were unable to undertake

in a systematic and in-depth manner, was to offer family caregivers the opportunity to discuss their anticipatory feelings of change in relation to grief and loss throughout their entire caregiving journey.

1.3 The Aim of this Research Journey

When I began this research journey in 2008, there was limited academic research which had been undertaken relating to anticipatory grief, loss and bereavement across the entire dementia caregiving journey. Although recent qualitative research undertaken by researchers such as Fetherstonhaugh, et al., (2017); Hellström and Torres (2016, 2013); Gillies (2011), and in particular the studies by Peacock, Hammond-Collins and Forbes (2016, 2014), have begun to address the experiential issues of change, grief and loss by family caregivers. My research study not only expands on previous research, but also builds on research which I had previously undertaken for my MSc in Dementia dissertation entitled, *The Journey from Dementia Diagnosis to Final Bereavement: An explanation of grief and bereavement experienced by male carers*. This former study explores the experiences of older male caregivers[2], who were bereaved and had previously undertaken the role of primary caregiver for their spousal partner. In retrospect I now feel that this initial study was very much a reconnaissance exercise for my exploratory return to this specific topic of research.

My rationale for undertaking both research studies is that I feel that there is more to examine with regard to the lived-experience of family caregivers within this complex landscape of care. Therefore the aim of this research study is:

> the exploration, in part retrospectively, of the complex and emotional aspects of the fluctuating perceptions of self experienced by thirty family caregivers in response to change, grief, loss and bereavement during their entire dementia caregiving journey.

[2] My MSc in Dementia dissertation was submitted in 2008 and involved research undertaken with six male participants aged between 80-85 years of age living in the locality in which I worked.

However, drawing on my previous research experience I realised the necessity of reflecting on the way in which I would undertake this in-depth research journey, the methodological approach I would utilise and the research participants who could be involved.

1.4 Terminology Used on the Research Journey

For the purpose of continuity and drawing on my practice-based and academic experience, the term "*caregivers*" will be used throughout this document with reference to family members involved with this research study. Caregivers involved are also referred to as *"participants"* or from a more personalised perspective by the application of a pseudonym. In addition, the term "*living with dementia"* is attributed to both the family caregiver and the person with dementia. The oft-quoted metaphor of *"journey"* is also applied. This is simply because people living with dementia whom I have had the pleasure of working with, both at practice and academic level, referred to their experiences of living with dementia as being firmly embedded within "*their*" journey of care. The metaphor of the caregiving journey is replicated in research, not only in dementia-related studies, as specifically highlighted by Davis, (2011); Fetherstonhaugh, et al., (2017); Fortinsky et al., (2002); Gillies, (2011); Peacock and Hammond-Collins (2014); Teel and Carson, (2003); Zimmerman (2013), but also other health-related research such as cancer care (Leydon, Bynoe-Sutherland and Coleman, (2003). In doing so it offers a recognisable definition as to the various aspects of not only personal experiences relating to change, but also disease trajectory and the negotiation of accessing health and social care services.

1.5 Review of Chapter One

The first part of this chapter offers a brief mise-en-scène description of the dementia caregiving landscape in the UK, as well as outlining my work-based background and the reasons why I have chosen this specific topic of research. Within this chapter I have also defined the aim of my study and the application of terminology in describing the experiences of the study participants. In chapter two of this document I review, synthesise and discuss current literature relating to the experiences of dementia caregiving by family caregivers.

Chapter Two

Exploring the Landscape of Dementia Care

2.0 Introduction

This chapter is formulated into six parts; with part one offering an exploratory view and synthesis of research literature pertinent to dementia caregiving. I have further structured this chapter with part two addressing the development of dementia care policy and the emergence of the role of family caregivers. Part three relates to aspects of caregiving, addressing the differential experiences of spousal caregivers and adult-caregiving children. In part four, I narrow the lens to explore the theoretical concepts of being, self and attachment. The penultimate section of this chapter, part five, draws on the interdisciplinary perspectives in relation to the epistemological concepts and ontological understanding of the complexities of change, grief, loss and bereavement. Finally, part six is a review of this chapter.

2.1 Within the Virtual and Non-Virtual World of Related Literature

To identify gaps in dementia research with regard to the experiences of family caregivers during their entire caregiving journey and relating to the aim of this study, an initial search of e-journal resources was undertaken in 2008 using the following internet-based bibliographic databases: Google Scholar; PsychINFO; Web of Science; Cumulative Index of Nursing and Allied Health Literature (CINAHL). In addition I was also alerted to new research studies via email alerts from specific e-journal publications[3]. This search was limited to articles published in the English language from 1995 onwards. Key terms applied to this search were: "family caregiving AND dementia or Alzheimer's disease". However, this initial search into the virtual world of e-journal resources presented a superfluity of material in generating an overwhelming literary landscape of over 3,000 papers.

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[3] Peer reviewed articles from e-journals included: Aging and Heath; Ageing and Society; Dementia; The Gerontologist; Family Relations; The Journal of Family Nursing; Marriage and the Family; Social Health and Illness.

As Emslie (2005) suggests, the titles and abstracts of resources can often be misleading and I certainly found this to be my experience. Therefore, a second review of literature which applied the elements of the inclusion and exclusion criteria, as outlined in Table 1, was undertaken in 2009.

Table 1: Inclusion and Exclusion Criteria of Literature

Inclusion	**Exclusion**
➢ Dementia studies primarily using a qualitative methodology. ➢ Exploring the subjective experiences of participants who were defined as being caregivers (who were family members regardless of their relationship to the cared-for-person). ➢ Review of studies that were undertaken in English (although not necessarily undertaken in the UK). ➢ Articles published from 1995 onwards.	➢ Dementia studies using a quantitative positivist methodology (minus a qualitative component of analysis). ➢ E-journals which were not peer-reviewed. ➢ Writing based on anecdotal accounts and lacking robust critical analysis. ➢ E-journals not written in English. ➢ E-journals published before 1995 which were not considered to be seminal dementia-related research.

In addition, the application of the terms and variant terminologies which replicated not only methodologies relating to dementia caregiving, but also addressed the aspects of experiential change and loss of caregivers were also applied. This second search strategy, included the terms and phrases: "dementia AND family caregivers"; "caregiving AND burden"; "caregiver relationship" and "caregiver experience". To assist in this search the thematic phraseology of dementia-specific terms replicating the research undertaken by Pauline Boss (1999; 2006) with regard to ambiguity, grief and loss were also applied. Search terms included a combination of: "dementia caregiving AND loss"; "dementia AND gender"; "ambiguous loss"; "anticipatory grief AND dementia"; "attachment AND loss" and "wellbeing AND caregiving".

This second search offered an extensive, although more manageable, result of 206 topic related and referenced resources. To address the aim of this research study the titles of literature resources generated were again screened to assess their relevance and adherence to the inclusion and exclusion criteria (Table 1). Subsequently, on reading the titles I found that over 120 were considered to be inappropriate. The reason being is that they directly adhered to my exclusion criteria of employing a quantitative methodology in adopting, as Creswell (2009) defines, a positivist approach whereby the researchers have predominantly concentrated on the development of statistical facts as an explanation of phenomena. These articles offered little or no in-depth subjective examination as to the experiential issues of family caregivers.

The abstracts of the remaining 80 papers were then screened, highlighting 28 papers which addressed specific aspects relating to other medical conditions and caregiving roles which were therefore excluded. For example, the diagnosis and treatment of cardiology and cancer care, with only a brief acknowledgement of dementia-related research being given. People with dementia may experience other health issues, pre- and post-dementia diagnosis and throughout their journey of living with dementia. However, I felt that inclusion of these articles would perhaps "*muddy the waters"* of knowledge relating to the all-exclusive experiential views of dementia caregivers in relation to the aim of this research study.

In total 52 articles were fully reviewed, although 8 papers were consequently viewed as being unacceptable given the limited content in discussing the experiences of family caregivers. A synopsis of each of the remaining 44 papers included in this second review of literature is given in the appendices (please see appendix 1.1). In addition the work of key authors regarded as seminal researchers in the fields of dementia care, gender issues in caregiving and bereavement, for example: Pauline Boss; Lori Kaplan; Tom Kitwood; Lore K Wright; Isabella Paoletti; Joan Tronto; Elizabeth Kübler-Ross; Franklyn Sills; Robert Fulton and David Gottesman were accessed and reviewed. To ensure that a broad overview of the experiences of family caregivers was fully addressed in this research process, relevant resources also included grey literature, as well UK and European based dementia care policy developments relating to the various aspects of dementia care. These aspects included the emergence of informal caregiving, dementia diagnosis, dementia care, palliative and end of life.

Given the duration of this research study, which is discussed in chapter 3 section 3.6 of this document, a third review of literature was undertaken in 2016 to ensure the capture of the development of dementia research since 2009. The terms and variant terminologies previously used in the second literature research strategy, undertaken in 2009 and adhering to the inclusion and exclusion criteria (Table 1), were again applied. However, search terms not only included the combination of: "dementia caregiving AND loss"; "dementia AND gender"; "ambiguous loss"; "anticipatory grief AND dementia"; "attachment AND loss" and "wellbeing AND caregiving", but also the germane phrase "dementia caregiving journey". This third research strategy proffered a total of 98 articles.

After abstract screening a total of 76 papers were considered not to be eligible for inclusion, either because they were duplicate papers, or due to their predominant quantitative methodological approach. The full contents of the remaining 23 papers were subsequently reviewed and the search was further supplemented with hand searching, which enabled the checking of references of other articles. In total 41 peer-reviewed articles were included in this third and final review of literature. A synopsis of each of the papers is given in the appendices (please see appendix 1.2). To further broaden the panoramic vista of the dementia caregivers' lived-experience, literature and non-digitised material relating to selfhood, attachment theory, grief and loss, as well as auto-biographical examples apposite to the experiential changes of caregiving were also appraised.

The review and discussion of literature begins with a macro-level approach in the examination of living within the world of dementia care, specifically addressing the development of pathways of care, policy development and care in the community. The review of literature continues with regard to the experiential issues and aspects of dementia caregiving relationships and gender. Finally, from a micro-level I examine the theoretical concepts of emotional individuality in relation to self, attachment and loss in relation to caregiving.

2.2 Living within the World of Dementia Care

The characteristics of dementia are difficult to define, but are associated with the progressive decline and global impairment of higher cortical functions. This incorporates memory loss and may

include language impairment, the ongoing capacity to resolve the experiential difficulties of day-to-day living, maintaining appropriate social skills, emotional capacity and changes in personality (DH, 2009; Hughes, 2011). In addition to these changes, a person with dementia may also develop psychological symptoms relating to depression and psychosis (National Institute of Clinical Excellence (NICE), 2010). Also, out-of-character behaviours may also be exhibited by the person with dementia. Such as difficulties relating to self-neglect, aggression, sleep disturbance or disinhibited sexual behaviour and excessive walking, which may be viewed as challenging by family caregivers and care workers (DH, 2009; Knapp et al., 2007; Hughes, 2011; Kjällman-Alm, Norbergh and Hellzen, 2013; O'Shaughnessy et al., 2010). However, Hughes, (2011) further highlights that as their condition progresses, many people with dementia do retain positive personality traits and personal attributes.

2.2.1 The Development of Pathways and Guidelines of Care

In the last forty to fifty years there has been an ongoing shift in the place of care of people living with dementia from hospital or large institutions, to care being undertaken within a community setting (Alzheimer's Society, 2014; Knapp et al., 2007). It is estimated that two thirds of the 850,000 people with dementia in the UK now live in the community, while one third reside within a permanent residential care home environment (Alzheimer's Society, 2014). The closure of hospitals, as well as the reduction of available hospital beds and time actually spent in hospital or institutional settings by patients, has heralded the introduction of new pathways of care.

With the development of healthcare pathways, the sociologist M. L. Etheridge offers a definition stating that they are "*geographic maps of managed care"* (1986: 3). Arguing that this assists in the elimination of boundaries associated with time and space within the health care system and further suggests that this cartographical redrawing of healthcare territories empowers us *"to chart the way for truly patient-centred care"* (1986: 4). However, nineteen years on from Etheridge's view, Pinder and colleagues in their paper: *What's in a care pathway: Towards a cultural cartography of the new National Health Service*, charter the course of care pathways as being *"direct descendants of the time-task matrix approach of Gantt charts*" (2005: 761). Pinder et al. further assert that care pathways have been widely regarded as helpful in directing patients and family caregivers through

the complexities of the health care system. Whether they are, "*anticipated recovery pathways; integrated care pathways; coordinated care pathways; or care maps*" (ibid: 762). Nonetheless, they question the proliferation of map-making in the provision of equitable healthcare services, by suggesting that care pathways are ideological constructs. Constructs which they argue have become the tools of choice, often utilised in the promotion of "*joined-up services and territorial expansionism"* and the emergence of "*hybrid professional approaches"* (ibid: 763). Furthermore, they assert that changes within organisations and the redrawing of professional boundaries may not necessarily conclude in achieving the advancement of the quality of care, or the optimal allocation of resources for both healthcare providers and service recipients.

In England the health and social care policy agenda of the 1990s and the early years of the 21st century established family caregivers as a prominent group. For the first time they were made the key figure of policy development, with the implementation of the Carers Act (DH, 1995a), the Carers and Disabled Children Act (DH, 2000) and the Carers Act (DH, 2004). In 2001 the Department of Health published the National Service Framework for Older People (NSFOP: (DH), 2001). The NSFOP began a ten-year strategy to provide comprehensive specialist older persons' mental health services, which integrates high quality health and social care services for older people, as well as including the needs of younger people with dementia. The framework also encourages the concept of community-based care and the recognition of family caregivers as being key figures. In addition, it recommends a person-centred approach to dementia care, echoing the work of Kitwood (1997).

In *Let's Make it Happen*: The National Service Framework for Older People (Alzheimer's Society, 2002), a briefing and local action plan for staff, volunteers and supporters of the Alzheimer's Society, was viewed as a welcome commitment made by the NSFOP (DH, 2001) to end age discrimination. It cited an act of encouragement to the involvement of older people in the structure which manages and regulates health and social care, as well as addressing some of the key problems of access to care by older people. The framework highlighted eight national standards which underpin these themes, with two standards being of particular consideration in relation to the care of people living with dementia. Namely, standard (2), relating to person-centred care, published in April 2003 and standard (7), appertaining to mental health, published in April 2004.

In their clinical guidelines the National Institute for Health and Clinical Excellence (NICE, 2006) emphasised the need to support people living with dementia with regard to health and social care. One of the central themes of these guidelines highlights early diagnosis of dementia in primary care, as well as the availability of knowledge for general practitioners in the provision of services offered locally by the health, statutory and voluntary sectors.

One year later, the Dementia UK report (Alzheimer's Society, 2007), the first major study on the social and economic impact of dementia in the UK, emphasises that during the first decade of the 21st century and despite areas of good practice, there is still evidence that suggests a growing failure in the services being offered to and received by older people with mental health problems. This concurs with the findings reported in The National Service Framework for Mental Health – *Five Years On* (DH, 2004) and *Better Health in Old Age* (DH, 2004), relating to not only older people, but also to a radical change to the financing system.

During this period the clearest guidance on policy relating to the provision, commissioning and integration of specialist older persons' mental health services is included in the report *Everybody's Business,* published by the Care Services Improvement Partnership (CSIP, 2005). The report notes that despite the significant achievements of the NSF for mental health and older people (DH, 2001), as well as the agreement in National Directors' reviews of NSF implementation (DH, 2004), there are still particular challenges in delivering better mental health services for older people. This is due in part to the fact that older adults with mental health problems have not benefited from some of the service developments and provision offered for younger adults. In addition developments in older people's services were not always seen as fully addressing their mental health needs.

In terms of dementia, the House of Commons Committee of Public Accounts in their document, *Improving dementia services in England - an interim report* (2009-2010) argue that dementia is still very much a hidden disease, comparing it to the experiences of people with cancer in the 1950s. With regard to finance, Knapp et al., (2007) state that the direct costs of Alzheimer's disease alone exceed the total cost of stroke, cancer and heart disease, with the Alzheimer's Society (2015) arguing that this figure remains the same.

In the last decade there has been increasing recognition as to the value of adopting a palliative care approach for life-limiting health conditions other than cancer care, such as cardiac failure and respiratory disease. In England, the End of Life Care Strategy, *Promoting high quality care for all adults at the end of life* (DH, 2008) for example, maps out the essential elements of support and care not only for the cared-for-person as the end of their life approaches, but also for their family members. This strategy draws from the experience of a range of other sources and examples of excellent practice, highlighting the need for the provision of: high quality services in a variety of care settings; assessment and care planning; ongoing care co-ordination; care before and after death; information and support for caregivers and other family members; as well as the spiritual needs of both the cared-for-person and family caregivers.

In terms of the introduction of healthcare guidelines and frameworks relating to dementia and palliative care Lee et al., (2015) report on the views of interview participants drawn from a variety of academic, health, statutory and voluntary sectors. Lee and colleagues state that in line with the policy of improving end of life care in England "*there has been an extensive dissemination of good palliative care practice guidelines*" (ibid: 7) in relation, for example, to the Gold Standards Framework (GSF) and other care pathways, such as the Liverpool Care Pathway for the Dying Patient (LCP) and the Preferred Priorities for Care (PPC). They report that interview participants reflect a multiplicity of opinions as to the beneficial and non-beneficial aspects of the interpretation and implementation of guidelines within their care-practice environment. They further suggest that frameworks cannot only inform good practice in relation to offering good end of life care for people living with dementia, but also enhance the enablement of knowing the person with dementia and engendering compassionate care. However, they conclude that guidelines such as the GSF whilst offering an approach for practice change, "*the service level implementation can be both enabled and constrained by leadership and existing guidelines and protocols*" (ibid: 9).

Developed in the late 1990s by the Royal Liverpool University Hospital and the Marie Curie Hospice as a response to the recognition of the lack of comfort and dignity experienced by patients at the end of their life, the LCP had been extended to the provision of good care for people in their final days of life. This provision was applicable to patients, whether they were residing in hospitals, nursing homes or within their own homes. However, growing criticism of the LCP led to a review,

which was independent of both the Government and the National Health Service (NHS), of the use and application of the LCP in England. Led by Baroness Julia Neuberger and her colleagues, their review document entitled *More Care, Less Pathway: A Review of the Liverpool Care Pathway* (2013) highlights evidence taken from interviews with clinicians and members of the public who had experience of the implementation and receipt of LCP. In addition, the authors reviewed academic literature, as well as reporting on the wider consultation process with the general public.

The underlying factor of the review highlighted in this report related to poor understanding among clinicians of existing guidance in care for the dying. In addition, the authors also cited the unwillingness of clinicians to engage in discussions with not only patients, but also their caregivers and relatives as to the clinical uncertainties which accompany end of life care. The use of terminology was also emphasised, especially associated with language and the name *Liverpool Care Pathway*; specifically the application of the term '*pathway*'. The authors of the report argue that family members would perhaps be unable to understand the concept of the integration of care being offered and the concept of the integration care services. Inevitably, they assert that many relatives would misconstrue the term '*pathway*', seeing it as a one-way road to death, facilitated by clinicians. Nevertheless, the report offered recommendations with regard to the inclusion of a strand of care for the dying being included in the Vulnerable Older People's Plan (DH, 2013) stating that:

> The Government must therefore ensure that its arms-length bodies collaborate with the clinical professional bodies and other key players in the system, and inject considerable funding into the system, to ensure that guidance on care for the dying is properly understood and acted upon, and tick-box exercises are confined to the waste paper basket for ever (DH, 2013:11).

In conclusion, the authors of the 2013 review emphasise that no pathway, plan, or protocol can be a replacement for good clinical judgement, compassion and care.

2.2.2 New Directions

Appraising the development of care in the community from a sociological perspective, Janet Heaton, (1999) argues that by the 1970s the focus of the direction of the health care system

was to support people within their own homes and immediate locality. The expansion of this ideology and introduction of policies relating to community care meant that in addition to changes in the NHS, new services were developed and subsequently offered. The provision of services was not only being provided by the statutory sector, but also by flourishing voluntary sector organisations such as the Alzheimer's Disease Society.[4] The overall ethos was to address a better community response to older people living alone with mental health problems and, in particular, to those experiencing and living with dementia.

Writing in the 1970s, Bayley (1973) argues that the provision of community care was the beginning of the interpretation of care not only undertaken within the community, but also by the community. This was a period during which the emergence of ambiguous terms applied to caregiving undertaken by relatives occurred (Twigg, 1989). Such as, '*informal carers'*, *'lay carers'*, *'caregivers'*, *'family carers'* or *'carers'*, becoming the definitive terminology applied to individuals who were usually family members, providing unpaid assistance for their dependant relatives or friends living within the community environment (Alzheimer's Society, 2007; Heaton, 1999; Tremont, 2011). From a sociological viewpoint Parkes (1991) suggests, the role of family caregivers has developed into the main source of enablement and support to people being able to continue to live within their own homes and communal environments.

The concrete foundations of both UK government policy and the philosophy of person-centred dementia care being brought into practice can be traced back to the early 1990s, with the emergence of heightened sensitivity and a more inclusive practice agenda for people with dementia being set out in the National Health Service and Community Care Act (DH, 1990). Subsequent policy initiatives, such as improving standards of care across the spectrum of service provision, including user consultation and carer support were promoted by the Audit Commission reports: *Forget Me Not* (2000; 2002). However, researchers Knapp et al., (2007) argue that even though the Community Care Act (DH, 1990) encouraged individual flexibility with the devolvement of

[4] The Alzheimer's Disease Society (England, Wales and Northern Ireland) was renamed the Alzheimer's Society in 2000.

budgets to case/care managers, real progress has only been achieved comparatively recently. For example, direct payments, such as the transfer of social care funding to individuals to spend on a range of services to meet their personal care needs, were only extended during the early part of the 21st century. Although evidence suggests that even before the recent financial cuts, there has been a decrease in the rate of growth in keeping with the needs of older adults (Nuffield Trust, 2012).

2.2.3 Policy Development and Grass Roots Implementation

In February 2007, the UK government announced a National Strategy for Carers with the initial undertaking of an extensive consultation exercise with caregivers and voluntary organisations, such as Carers UK. This consultation process commenced in March 2007 and continued until January 2008. The final strategy, launched by the then Prime Minister, Gordon Brown, entitled *'Carers at the Heart of 21st Century Families and Communities*' (DH, 2008), includes a commitment of £255 million to create additional support for caregivers, as well as a ten-year vision outlining what this support should entail. It could be argued that the Carers' Strategy (DH, 2008) and Lord Darzi's review of the National Health Service entitled: *High Quality Care for All* (DH, 2008) can be seen as part of the government's overall range of vision relating to the health and social care agenda, which espouses the improvement of care for people living with dementia.

In response to this challenge, in 2007, the UK government identified dementia as a national priority. A nation-wide public consultation programme involving various stakeholders, including people living with dementia was undertaken to develop a National Dementia Strategy (DH, 2008) and implementation plan for England. Findings from the public consultation process and subsequent introduction of the role of dementia advisers highlight:

> One of the most clear and consistent messages emerging from discussion with people with dementia and their carers has been the desire for there to be someone who they can approach for help and advice at any stage of the illness – "*someone to be with us on the journey"* (DH, 2008: 40)

From this, the document *Living Well with Dementia:* A National Dementia Strategy for England (DH, 2009) was implemented and seen as a catalyst for a change in the way in which people living with dementia are viewed and cared for in England. The outcome focus of the strategy consists of

seventeen objectives addressing three broad themes: early diagnosis and support; raising awareness and understanding, and living well with dementia. Four objectives of the strategy were extremely pertinent to the remit of my Alzheimer's Society role in offering support to people living with dementia. Six years later they were seen as part of the priority areas for the North East region identified by the North of England Mental Health Development Unit (NEMHDU, 2015). Specifically: objective (2) good-quality early diagnosis and intervention for all; objective (4) relating to easy access to care, support and advice following diagnosis, with objective (5) outlining the development of structured peer support and learning networks, and objective (12) addressing improved end of life care for people with dementia (ibid: 39).

In 2010 the UK coalition government published the framework document: Improving outcomes and supporting transparency: *A public health outcomes framework for England* (DH, 2010-2016), in which some of the original objectives of the National Dementia Strategy (NDS: DH, 2009) were not considered as a priority. This related to objective (5) with regard to structured peer support (NEMHDU, 2015). However, Banerjee (2010), writing one year on from the implementation of the NDS for England, argues that the strategy was a response to the reality that:

> The large majority of people with dementia and their family carers do not benefit from positive intervention and support that can promote wellbeing and prevent crises for all involved (ibid:917)

With regard to objective (4) of the NDS strategy (DH, 2009), the majority of the branches within the Alzheimer's Society, specifically within the northern region of England, provided similar roles as undertaken by the dementia advisers. These were family or carer support workers who were salaried members of staff, with a remit of offering support to people living with dementia within the locality. The introduction of dementia advisers echoes the central tenet of the wishes of people living with dementia whom I was working with during this period. Essentially, people living with dementia being able to access a "*one stop shop"*. In essence preferably enabling them to have a continuous relationship with one individual, whom they felt they could approach with regard to receiving appropriate information. Clarke, Alexjuk and Gibb (2011) argue that the provision of information is a core focus of policy and practice in dementia care, citing the encouragement of a person-centred approach in the sharing of information and knowledge. Relating to receiving

practical and emotional support, the NDS (DH, 2009) highlights the response to the consultation process with regard to objective (5) in the development of peer support networks as:

> One clear message we have received from people with dementia and their carers is that they draw significant benefit from being able to talk to other people living with dementia and their carers, to exchange practical advice and emotional support (DH, 2008: 41).

With regard to objective (12) of the NDS, (DH, 2009) appertaining to end of life care and dementia, the Alzheimer's Society report, Dementia 2012*: A National Challenge* (2012), highlights the overall lack of the provision of services being offered, stating that:

> Despite the significant spend on dementia, this is not being developed effectively and too many people are not provided with good quality care and support that meets their needs and aspirations. Furthermore, the quality of care varies considerably across geographical areas (ibid: 4).

Following on from the announcement in 2012 by the then UK Prime Minister, David Cameron, relating to the *Challenge on Dementia* (DH, 2012), this report outlines not only additional research funding, but also the creation of dementia friendly communities, as well as the continued improvement of services relating to health and social care. The *Challenge on Dementia 2020* document (DH, 2015) augments these proposals, outlining the requirement of enhanced training and awareness. With significant care being offered post-diagnosis; as well as relating to support and appropriate advice for caregivers.

In a regional pilot project and evaluation report entitled: *Living Well with Dementia, A Participation and Engagement Programme for People with Dementia and their Carers* (NEMHDU, 2015)[5], the authors argue that despite the increase in policy focus, many people living with dementia are still being let down. They highlight seven key areas outlined in the NDS (DH, 2009) as being of priority concern in the North East region of England. Namely: good quality early

[5] Comprised of the design, delivery and evaluation of two pilot programmes undertaken by the North of England Mental Health Development Unit in the north and the south of the region in 2014 and involved '*expert reference groups'*, made up of not only people living with dementia, but also clinicians and other key stakeholders.

diagnosis; improved community support services; improved quality of care in general hospitals; housing support, including telecare support; living well with dementia in care homes; improved end of life care for people with dementia and a reduction of inappropriate prescribing of antipsychotic medication. The recommendations of the project evaluation summarises various aspects in achieving some of the objectives outlined in the Prime Minister's *Challenge on Dementia* 2020 document. These being the presentation of findings of the pilot programme to commissioners and providers of dementia services across the North East region. In addition, the embedding of this programme into the diagnostic pathway directly following diagnosis, as well as securing an academic partner to research the longer term impacts for participants. Also, highlighting the exploration of future funding and the establishment of a training programme to implement the *Living with Dementia* programme within the region being recognised (NEMHDU, 2015: 39).

2.3 Aspects of Caregiving

2.3.1 Gatekeepers to Diagnosis and Care Services

As previously highlighted, the experience of many family caregivers caring for a relative with dementia can be a protracted journey, expanding over many years. However, Hughes et al., (2006) state that dementia has now joined the ranks of those disorders and diseases where early recognition, detection and diagnosis are paramount. Nevertheless, people who experience symptoms of decline in cognitive ability may delay consulting their general practitioner (GP) for up to three years (Alzheimer's Society, 2002). The *Facing Dementia Survey* undertaken by Bond et al., (2004) attributes this delay to several factors, stating that seventy percent of caregivers report being unaware of the symptoms of dementia, with sixty four percent perceived as being in denial regarding the condition and fifty eight percent considering that the symptoms were an integral part of ageing. More recently the Alzheimer's Society report (2012) highlights that people living with dementia struggle to receive a diagnosis.

Adams (2006), undertaking a phenomenological study based on twenty semi-structured interviews with spousal caregivers and adult caregiving-daughters, states that many caregiver participants are initially hesitant about seeking, or indeed accepting assistance from clinicians. Their reason being that they wished to maintain the normality, their perceived *'status quo'* of their family life for as

long as possible. However, the pivotal role played by primary care workers, especially general practitioners as being the gatekeepers and brokers of this process, concurs with Standard (7) of the National Service Framework for Older People (NSFOP, DH, 2001), which recommends an integrated approach to the care of people with dementia. At the heart of which is:

> Early diagnosis in primary care and the availability of knowledge to general practitioners with regards to services offered locally by the statutory and voluntary sectors (ibid: 28).

The report *Improving Services and Support for People with Dementia* (National Audit Office, 2007) in reviewing the health and social care services available for people living with dementia in England, estimates that approximately two-thirds of people with dementia do not receive a formal diagnosis, or are referred to specialist services at any time during their illness. Eight years on from this report the Alzheimer's Society highlights that only forty four percent of people with dementia living in England, Wales and Northern Ireland receive a diagnosis (Alzheimer's Society, 2015). Another factor relating to diagnosis cited in this report reflects the reasons of general practitioners in specifically offering the diagnosis of dementia to family caregivers and not to the person with dementia which relates to:

> Not wishing to distress the patient, or risking that the patient may "*feel stigmatized, become depressed even to the point of despair, and become difficult to manage*" (Pinner and Bouman, 2003: 280).

Historically, referral has been viewed as a major stumbling block for the majority of general practitioners, who perhaps saw little point in early referral and who often under diagnosed dementia, or delayed diagnosis until things are so bad that psychiatric services are forced to respond (DH, 2012). A report by the Alzheimer's Society (2013), involving 382 general practitioners, highlights that many people with dementia are not being diagnosed, because they are not making an appointment to see their doctor. The *State of the Nation* report (DH, 2013) purports that less than half of people with dementia receive a diagnosis and that there is a huge disparity of support across the country. More recently an online survey involving 1,000 general practitioners suggests that some patients are forced to rely on family, friends and unpaid carers due to gaps in services (Alzheimer's Society, 2015).

One of the key commitments of the *Challenge on Dementia* document (DH, 2012) ensured that general practitioners, as well as other health professionals, make patients of 65 years and older aware of memory clinics and dementia assessment processes. Although the Alzheimer's Society states that diagnosis rates have risen slightly by two percent, to forty eight percent, this still equates to 416,000 (the remaining fifty two percent) of people with dementia who are not diagnosed. In addition, obtaining a diagnosis of dementia is geographically related to a '*postcode lottery'*, which results in many people still awaiting a formal diagnosis beyond the national recommended period of twelve weeks (Alzheimer's Society 2013).

If dementia is not diagnosed correctly, people living with dementia are denied the possibility from the very beginning of their journey of being able to make choices for themselves. They are unable to plan for their future and the repercussions of this may lead to being unable to access practical, social and psychological support, or the appropriate pharmacological treatments that are available (Alzheimer's Society, 2007; 2013). However, the fear of dementia is prevalent suggest Bond and Corner (2004). Also, given the negative associations of Alzheimer's disease and other forms of dementia there is still much work to be done to raise awareness (Batsch and Mittelman, 2012). Nonetheless, with regard to awareness researchers such as Hughes (2011) highlight that our comprehension of health and disease is often assembled and facilitated by information acquired via the media.

2.3.2 Living with Dementia

From the family caregivers' perspective, caring for someone with dementia is related to more than the progressive cognitive losses experienced by their relative, the person with dementia. Researchers such as Brodaty & Donkin, (2009) and Brodaty et al., (2005) argue that there are many other possible experiential '*losses*' involved. This includes the gradual loss of the cared-for-person and their role within the family, as reported by de Witt, Ploeg, and Black (2010), as well as experiential changes of the previous relationship between the caregiver and cared-for family member, purported by Stokes, Combes and Stokes (2014). In addition, possible threats to the caregivers' sense of self may also be experienced (Skaalvik, et al., 2016). Although Doka (2005),

writing from a bereavement perspective, argues that the first loss experienced by people living with dementia is the loss of their past.

Conversely, there are also experiential acquisitions, both physically and emotionally acquired by caregivers during and beyond their caregiving role. The experience from recognising the discrete changes in the cognitive health of the person with dementia, to the end of their life can be a protracted, changeable and dynamic process (Ducharme et al., 2011; Lin, Macmillan and Brown, 2011). Subsequently, the central aspects of day-to-day living and caring within the landscape of dementia care may often mean that the caring role being provided by family caregivers often necessitates significant expenditure of their personal time and energy (O'Rouke and Tuokko, 2000). Also, the repercussions of undertaking the role of caregiving over an extended period of time can be both physically and psychologically exhausting (Brodaty and Green, 2002; Cooper et al., 2009; O'Rouke and Tuokko, 2000). Affecting not only the caregiver themselves, but as Knapp et al. (2004) suggest, impacting the entire family system.

Gillies, (2011) in discussing the caregiver's journey through dementia outlines the complexities of the caregiving role as being associated with an attempt to maintain continuity by the caregiver, whilst negotiating the experiential losses between themselves and the cared-for-person. This she suggests is undertaken within the "*shifting ground of a progressive illness"* (ibid: 657). The extensive aspects of experiential loss for caring for a family member with dementia are twice the amount of that of caregivers caring for a relative with cardiac problems. Also, for dementia caregivers, due to the intensity of their caregiving role, there is also the possibility of being unable to maintain social relationships with family and friends outside of their caring environment. This adds to their experience of social isolation and loneliness (Brodaty and Green, 2002; Cascioli et al., 2008; Lin, Macmillan and Brown 2011), particularly for spousal caregivers (Adams, 2006). In addition, caregivers may also experience detrimental financial consequences relating to their employment status, lifestyle and wellbeing (Lee and Lintern, 2010; O'Rouke and Tuokko, 2000; O'Shaughnessy, 2010).

During their caregiver journey family caregivers can choose to access supplementary support for both themselves and the cared-for-person provided by health, statutory and voluntary services, both

within and out-with the home environment. However, this is of course predicated on the fact that they are not only made aware of the provision of services, but also if such services are indeed available within their locality (DiBartolo, 2000). In addition Peel and Harding (2014) argue that given that the dementia journey is often protracted and undertaken over several years, the accessing of specific services is often commenced incrementally over time. Nonetheless, they also suggest that during the dementia journey "*there are periods which may necessitate a step-wise process"* (ibid: 643), in which the requirements of services are often abruptly required. This is frequently in response to a crisis event, or tipping point (Peacock, Hammond-Collins and Forbes, 2014), relating to episodes of ill-health being experienced by either the caregiver or cared-for-person. Peel and Harding (2014) further suggest that the accessing of health and social care services necessitates complex negotiation and organisation skills by the caregiver over an extended period of time. Requiring an ability to seek out and then to orientate themselves within the vast maze of services provided at health, social and community level. However, researchers such as Cascioli et al. (2008); Shanley, Russell and Middleton, (2011) highlight that formal assistance is often perceived by family caregivers as being insufficient in meeting the needs of caring for their family member.

Then as the journey of living with dementia continues, the person with dementia may leave the family home and enter permanent residential care, as their experience of dementia progresses. Whether this is undertaken as a conscious decision by the family or in response to a crisis, this event invariably prompts a redefining of the caregiving role undertaken by family members (Lin, Macmillan and Brown, 2011). With regard to spousal caregivers, this outcome is often interpreted as an '*uncoupling*' between themselves and their family member, given that they are no longer living with their spousal partner (Hennings, Froggatt and Payne, 2013). As such it creates a liminal state of *'quasi-widowhood'* within their relationship (Rosenthal and Dawson, 1991). For some spousal caregivers having undertaken the caring role over many years, this may have become a dominant feature of their self-identity, their raison d'être in life (Brodaty and Green, 2002). In losing their role as primary caregiver, Kaplan (2001) argues that this can subsequently lead to caregivers experiencing ambiguity in the future sharing of their role with care workers. Whilst Stevenson (1999) purports that invariably the perspectives of caregivers relating to long-term care are varied and dependent on such factors as the length of time actually spent in providing care prior to the cared-for-person entering a permanent residential care environment.

The placement of their family member outside of the family home and into a permanent residential care setting may also be viewed as a devastating experience for the caregiving relative, especially if there was little or no forward planning prior to admission (Rosenthal and Dawson, 1992). Family caregivers may wish to remain involved with the care of their family member, even though this may be detrimental to their own physical and mental well-being (Roach et al., 2014). A study undertaken by Braun et al. (2009) highlights the safeguard actions by family members against possible loss of '*familyhood*'. Whilst researchers such as Craft and Willadsen (1992) offer a clear sociological definition of the family as operating as a historical unit, which resonates with the experiences of families living with dementia:

> A social context of two or more people characterised by mutual attachment, caring, long-term commitment, and responsibility to provide individual growth, supportive relationships, health of members and of the unit, and maintenance of the organisation and system during constant individual, family and societal change (ibid: 519).

In contrast post-placement some family members may even cease to be fully involved in the life of their relative. However, from a sociological perspective Nay (1995) suggests that this could be viewed in terms of a means of self-preservation by caregivers in being emotionally unable to withstand the further physical and cognitive decline of their family member. Nevertheless, such situations of a lack of family involvement often receive criticism by care staff in being unable to comprehend the emotive experiences of family members. Nay further cites that for those family caregivers who do remain within the caregiving relationship, this may result in them having negative experiences of a sense of *"an inner circle constructed around the resident by staff"* (ibid: 24). In addition, Nay argues that this may further perpetuate the experiential feelings of isolation by family members, given their perception that they are no longer the sole person providing care to their relative. In particular, this correlates to the lack of continuity of information given to them by care staff regarding their cared-for relative. The ambiguity of this lived-experience is outlined in a longitudinal narrative study of spousal caregivers of people living in nursing home environments, undertaken by Hennings, Froggatt and Payne (2013). The authors highlight the confusing nature of the caregiving experience of family members as being:

> A struggle to live in "*two worlds*", the world of the nursing home and the world of wider society (ibid: 689)

Kay de Vries (2003) argues that with regards to palliative care, the needs of people living with dementia have now been recognised. This corresponds to the growing interest relating to the quality of life for older people in general and recognition that care during this period should be extended beyond cancer (DH, 2003; Hughes et al., 2010). Nonetheless, researchers such as Treloar, Crugel and Adamis (2009) suggest that the provision of palliative and end of life care for people with dementia is challenging, due in part to the variant time course of the illness in comparison to that of cancer. However, Hughes, (2011) asserts that the goal of all dementia care requires the maintenance and further enhancement of the quality of life for the cared-for-person. In addition, he further argues that the ongoing needs of family members should be addressed, especially at the palliative and end of life point of their caregiving journey.

The National Institute for Clinical Excellence (NICE) has defined supportive care for people with cancer, but with some modification the definition can be used for people with any life-threatening condition (NICE, 2006). Within the field of dementia studies there is an increasing awareness of the potential outcomes of applying a person-centred care approach during the palliative care period and moving towards the end of life of the person with dementia (Downs et al., 2006; Hughes, 2004). Yet despite the availability of generic definitions of palliative care, and local eligibility criteria, the European Association for Palliative Care (EAPC) suggests that it is unclear as to exactly what palliative care in dementia entails (EAPC, 2009) with researchers such as Treloar, Crugel and Adams (2009) highlighting a continuous lack of clarity. However, the National Council for Palliative Care (NCPC) offers the definition of palliative care as being:

> The active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments. (NCPC, 2015)

The DH strategy: *End of Life Care Strategy: Promoting high quality care for all adults at the end of life*, published in 2008, cites the NCPC definition of end of life care as:

> Assisting all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support. (DH, 2008: 47)

However, the strategy authors highlight that the recognition of the commencement of the requirement of end of life care is based on the perspectives of the individual person, as well as those of professional care workers. Yet before this point of the journey is reached, people living with dementia may or may not undertake forward planning in relation with the end of life wishes of the cared-for-person.

Stipulated by the National Institute for Clinical Excellence and Social Care Institute for Excellence (NICE, 2006) and part of the National Health Service – End of Life Care Programme (2007), Advance Care Planning (ACP) involves discussions between the person with dementia and professional care staff about future care requirements. Exley et al., (2009) highlight that these discussions appertain to:

> The person's preferences regarding both the type of care they would wish to receive and the setting or location in which they wish to be cared for' (ibid: 18).

However, these considerations are seldom undertaken by people with dementia, or indeed with the involvement of family members (Dickinson, et al., 2013). The researchers further argue that for the inclusion of the documented wishes of the person with dementia to be addressed, they should be based on the person being asked earlier in their dementia journey, whilst they may still have the capacity to make these decisions. However, in a qualitative study investigating older people's approach to forward planning, Samsi and Manthorpe report that participants expressed a *"live for today, tomorrow you die"* (2011: 54) philosophy to life. Although Robinson and colleagues (2012), in a systematic review of the effectiveness of ACP interventions of people with cognitive impairment and dementia living in nursing homes, highlight that discussions may take place far too late in their journey.

In a recent white paper undertaken with recommendations from the European Association of Palliative Care (EAPC), van der Steen et al., (2013) carried out a Delphi study involving experts

from across the world. They define the optimal palliative care in older people with dementia, highlighting immediate consensus on eight recommendations relating to: person-centred care; communication and shared decision-making; optimal treatment of symptoms and providing treatment; setting care goals and advance planning; continuity of care; family care and involvement; education of the health care team; societal and ethical issues. However, the lowest priority for research identified related to societal and ethical issues, and psychosocial and spiritual support. Possible explanations given by the authors for this were: an under-representation of panellists with expertise within these areas; a general focus on medical aspects of palliative care or a perception of research being less efficient in its ability to address these aspects specifically.

In a follow up article: *Achieving Consensus and Controversy Around Applicability of Palliative Care to Dementia,* van der Steen et al., (2016) discuss that further studies should be undertaken to examine the benefits of palliative care, especially during the early stages of dementia. In addition, they outline concerns relating to local resistance and early implementation of palliative care versus ACP issues. Citing the requirement of innovative solutions in care practice and the maintenance of an approach, which enables people living with dementia to convey their concerns, not only with regards to dementia diagnosis, but also their future wishes as the journey with dementia comes to an end.

2.3.3 The Role of Caregiving

The Alzheimer's Society estimates that in 2013, a total of 340,000,000 hours were spent by family caregivers caring for someone with dementia, equating to a total of more than 150,000 years (Alzheimer's Society, 2014). Nonetheless, family caregivers assume their caring role for a variety of reasons. They become caregivers because of a sense of commitment and duty to their family member. This is often to the detriment to the caregiver's emotional and physical wellbeing (O'Rouke and Tuokko, 2000). They may embrace their new role as caregiver whole-heartedly, because they have shared a lifetime of experience and love with a person who may no longer recognise them for who they are within that relationship (Chan et al., 2012; Peacock, Hammond-Collins and Forbes, 2014). In some cases, the role of caregiver means providing support in a relationship which has been physically and emotionally distant (O'Rouke and Tuokko, 2000).

Other studies have suggested that some family caregivers are ill-prepared in commencing their caregiving role (Ducharme et al., 2011). In contrast, Peacock, Hammond-Collins and Forbes (2014) highlight the efforts undertaken by family members in planning and implementing the future needs of their cared-for relative.

Qualitative and longitudinal research undertaken by Lin, Macmillan and Brown (2011) explores the experiential perspectives of family caregivers and outlines four categories defined by participants with regard to their caregiving role. They highlight the perceived view of study participants in connection to the thematic experiences of*: my life changed; commitment; responsibility;* and *duty a*nd *support*. However, Bender (2003) argues that for most family caregivers, especially spousal partners, the reality of caregiving is that of change and responsibility, often undertaken within a *'closed'* situation. A position in which the caregiver is either physically and/or emotionally unable to leave, or can do so with only the greatest difficulty. Conde-Sala et al. (2010) purport a different perspective of spousal caregivers, suggesting that the role of caring for their partner is viewed as part of their marital duties and is not perceived as being role reversal. With Davis (2011) suggesting that the marriage relationship is a blending of the concepts of *'me'* and *'you'*, defining this collectively as an '*us identity'*. This is in contrast to the perceptions of adult-caregiving-daughters, who experience change in both their role within the family and also their lifestyle (Conde-Sala et al., 2010), and becoming parent to their own parent (Kjällman-Alm et al., 2013). Adult caregiving-children caring for a relative with dementia are often employed and, in contrast to the spousal caregiver, are less likely to reside with the cared-for-person (Kjällman-Alm et al., 2013).

In terms of caregiving, Heaton (1999) identifies the informal care research genre as a definite development by researchers in the sophisticated classification of family carers. Gaugler et al. (2005), in their longitudinal research exploring the experiences of caregiving, seek to professionalise the role of family caregivers by referring to the *'caregiving career'*. Whilst Netto, Jenny and Yap (2009) suggest that for some family carers the definitive term of *'carer'* may be deemed to be viewed as an unwelcome and/or culturally inappropriate description. A label applied by others, which caregivers interpret as a failure to be recognised as an individual person and therefore a denial of their relationship with their cared-for family member. From a grief and

bereavement perspective, Parkes (1981) suggests that people may also object to the emotional content of the term carer, arguing for a semantic distinction between being viewed as a person caring *'for'* someone, to caring *'about'* someone.

Braun et al. (2009) highlight that caregiving is invariably undertaken with a dyadic relationship between the cared-for-person and their spousal partner or an adult child-caregiver. They highlight that this relationship subsequently develops into one which moves the equitable exchange of this relationship, to being one which places greater emphasis on the burden of care for the caregiver. Evaluating part of the National Dementia Strategy for England (2009), the authors of the Healthbridge Report (2013) offer interview participants' description of their perceived view of the role of caregiving within the family as being a *"full time job"* (Clarke et al., 2013: 201). Whereas Mace and Rabins (2012) maintain that the experiential perception of family caregivers relating to their day-to-day activities of caregiving in the community is often viewed as being that of a 36 hour day. Researchers such as Calasanti and Bowen (2006) assert that the intimate relationship within the care dyad assists in the protection of the cared-for-person. From a social work perspective and not specifically dementia-related, Biggs, Phillipson and Kingston (1995) suggest that undertaking care, especially within the community, is a development of a triadic association between the family caregivers, the cared-for-person and the professional care worker(s), from whom they are seeking support. Although they further argue that:

> Like all triangular relationships it is inherently rivalrous, as there is always the possibility of two members pairing off, thus forming a collusive alliance that to some extent excludes the third party (ibid: 73).

The authors proposes three types of collusiveness in which he suggests that: (1) the caregiver and cared-for-person collaborate against the professional care worker; (2) there is a dyadic alliance by the cared-for-person and the professional care worker against the caregiver and (3) where the professional care worker and caregiver work together to exclude the cared-for-person. This latter dyadic relationship is also highlighted by Shanley (2006) who purports that due to their cognitive impairment people with dementia may be in a position of being unable to be fully involved in the negotiation of their care package. Subsequent decisions relating to their care requirements are therefore made by others, particularly by their family caregiver (Fetherstonhaugh, et al., 2017).

2.3.4 Experiences of Caregiver Burden, Reciprocity and Wellbeing

The Office of National Statistics (ONS, 2007) highlights that one-third of all caregivers providing care for family members experience mental health problems. With two-thirds of caregivers who provide more than fifty hours of care per week, reporting that their health had been affected by carrying out their role. Gaugler et al. (2005) purport that mental health problems can be associated with behaviourial challenges experienced early in their caregiving journey, which will subsequently have a damaging impact on the emotional health of the caregiver. For example, Sanders et al., (2008) assert that the substantial time often allocated to caregiving leads to not only the consequential loss of freedom for the caregiver, but also detrimentally affects their physical and mental wellbeing.

Since the passing of the National Health Service and Community Care Act (1990), the shift from institutional to community care has been reported by researchers as increasing the burden of care placed on family caregivers. There is extensive literature relating to stress and burden as being the prevailing tapestry of caregiving experienced by family caregivers (Brodaty and Green, 2002; DiBartolo, 2000; Gaugler et al., 2005; Kim et al., 2012; Kjāllman et al., 2013; Netto, Jenny and Yap, 2009; Nolan et al., 2002; Norman et al., 2004). With researchers, such as Conde-Sala et al. (2010), stating that the phrase *'caregiver burden'* is often used to define this experience.

However, Bender (2003) suggests that figuratively the term burden has negative connotations for both the cared-for-person and the caregiver; arguing that a burden in everyday common parlance is grammatically defined as being *'heavy'* and *'passive'*. Researchers such as Hughes et al., (2006): Twigg and Aitken (1995) criticise the extensive representation of stress and burden reported in dementia care literature, suggesting that this engenders a medicalised view of the experiences of caregivers. Nevertheless, the sense of burden experienced by caregivers may be partially attributed to their own, as well as the cared-for-person's diminished internal locus of control. Other predictors of overcoming the stresses of burden include the caregiver's personality, coping style, as well as their gender and the availability of alternative and external caregiving support (Mikulincer and Shaver, 2008).

In contrast, researchers such as Lloyd, Patterson, and Muers (2016) contend that more positive outcomes are also associated with informal care. With Sanders et al., (2008) undertaking a study involving eighty five family caregivers living in urban areas, reporting that some study participants express experiential gains of personal and spiritual growth in caring for their family member. Those participants who did not highlight personalised gains perceived themselves as being isolated and undertaking their caregiving with relatively little support. Chappell and Reid (2002) argue that a much broader view of caring relationships within families should be undertaken, given that the model of burden is not universally experienced. However, they suggest that there is a paucity of longitudinal data which recognises the changing conditions within the caregiver and cared-for-person relationship stating that:

> It is precisely the dynamics involved in this evolutionary process that need to be researched before caregiver experience can be adequately understood (ibid: 179).

Researchers have also argued that dementia is not only a debilitating condition affecting the person with dementia, but almost always attributes negative experiences of the family caregiver. Although with regard to the notion of caregiver burden, Hellström, Nolan, and Lund (2007) suggest that within the spousal caregiver and cared-for-person dyad there is a nurturative perspective. They assert that there is a considerable contribution from both partners in an attempt to explore, cope with and maintain the relationship whilst living with dementia. Calasanti and Bowen (2006) describe that the experience of caregiving by husbands may be stressful, yet they display a greater willingness to adapt to roles previously undertaken by their cared-for wives, such as food preparation. Furlong and Wuest (2008) in contrast, highlight that caregiving wives often find the transition and adjustment of taking on roles which were previously the responsibility of their husbands to be a challenging experience. Although Calasanti and Bowen (2006) argue that this highlights the differing experiences of spousal caregivers whose expectations may be to care for their partner in old age, but they do not view this as a reversal of roles which is so often reported by adult-caregiving children.

When a family member becomes a caregiver, they may assume escalating emotional, physical as well as financial burdens over many years (Brodaty and Green, 2002; Kim, Rose and Kim, 2012). These physical and emotional demands can place the older caregiver at risk for compromised

health issues. Added to this, the lack of social support and appropriate coping skills can leave a caregiver at the mercy of depression, exhaustion, and exacerbated personal health conditions (Peacock, Hammond-Collins and Forbes, 2014; Adams et al., 2008; Norman et al., 2004). In addition, many family caregivers of people living with dementia express fears about self-care, particularly with regard to their own health problems and reliance on medication over a prolonged period of time (Peacock et al., 2016; Paoletti, 1998a, 1998c, 1999). Also, the persistence of negative indicators such as apathy and retreat may be even more deleterious, as this can often lead to a chronic alteration of the relationship between the caregiver and the person with dementia (Schultz and Sherwood, 2008).

Yet in contrast, writers such as Conde-Sala et al., (2010); Kim et al., (2012); Purves (2010) point out that from an experiential perspective the caregiving relationship may be perceived as being burdensome, but can be marked by some degree of interdependence or reciprocity. Lore K Wright in her foundational work relating to Alzheimer's disease and marriage reports that the quality of spousal interactions will:

> Contribute to viewing the relationship as either desirable with a projected future, or as oppressing and fostering wishes to escape. Yet even with difficult interactions, acceptance of the relationship can occur (1993: 46).

More recently, researchers such as Brodaty and Donkin (2009), Schultz and Sherwood (2008) highlight that spousal caregivers in particular report their caregiving role as being a satisfying experience, offering them the chance to reciprocate the love and care they received from their spousal partner. Chappell and Reid (2002) argue that a perceived perception of closeness within the cared-for and caregiving relationship may also sustain a sense of wellbeing for the caregiver. Emphasise that the feelings of positivity experienced by caregivers as possibly being beneficial in engendering resilience and thus being able to carry out and sustain their caregiving role. Schulz and Sherwood (2008), attributing caregivers' compassion for their partner, report that particularly within spousal relationships, there are also beneficial outcomes of caregiving. Equally, for example, Netto, Jenny and Philip (2009) highlight the further experiential enhancement of relationships of adult daughters in supporting their father within their caregiving role. However,

Twigg and Atkin (1995) succinctly suggest that informal caregiving takes place within the context of any relationship, whether it is good, bad or indifferent.

Within this relationship, given the trajectory of dementia, the psychological wellbeing of the caregiver is often vulnerable. However, religious practices have been reported as being beneficial by caregivers during their caregiving journey (Purves, 2010). Researchers such as Farran, Paun and Elliott (2003) define religious beliefs in terms of rituals and doctrines based on organised and formal belief systems which may be chosen by the individual, or as an existing part of their cultural heritage. Whilst Lin, Macmillan and Brown (2011) assert that church attendance for example, provides caregivers with an opportunity to not only maintain their social life, but that their belief system also aids them to identify and accept a greater meaning in relation to their caregiving situation. DiBartolo (2002) and Farran et al., (2003) offer accounts by family caregivers who emphasise spirituality, particularly at the end of life of their family member, enabling them to draw in their inner strength and connectedness to their sense of self, others and a perceived higher power. However, there appears to be a scarcity of literature relating to religious and spiritual practices undertaken by caregivers to stimulate feelings of wellbeing across their entire dementia caregiving journey.

A recent development in the last few years, particularly in the United States[6] (US), but also now in the UK, has been the introduction of Mindfulness Based Stress Reduction (MBSR) courses for people living with dementia (Litherland and Robson, 2014). Originally adapted from Buddhist meditation practices, it has been developed and utilised within clinical psychologist by Jon Kabat-Zinn (1982) to address the experiences of stress and anxiety by patients with chronic pain. Mindfulness is associated with the teaching of meditation skills, requiring participants to be *'present'* within the moment. In relation to dementia, Litherland and Robson (2014) report on a pilot study involving twelve people with dementia and eight family caregivers who attended 2.5 hour sessions over an eight week period. The authors highlight that in terms of relieving stress and

[6] The MBSR programme in the US relates to the development of the Life Enhancing Activities for Family Caregivers (LEAF) of people with dementia. The programme is offered by the School of Nursing, Osher Centre for Integrated Medicine, University of California.

anxiety, the sessions proved to be effective for all course participants. The eight family caregivers reported that the MBSR course had assisted them in gaining new skills and a sense of wellbeing in being able to deal with their thoughts and feelings regarding their family member.

2.3.5 Gender and the Caregiving Role

Researchers such as Kitwood (1997) and Purves (2010) highlight that when a diagnosis of dementia is given; this event often involves the re-negotiation and repositioning of roles and responsibilities within the entire family unit. This is in response to new situations and anticipated future expectations in relation to the way in which dementia affects not only the cared-for-person, but also other members of the family. Studies undertaken by Brodaty and Donkin (2009); Smith and Kobayashi (2002) focussing on the family as a social unit, place emphasis on the differential ways in which individuals interpret their new situation and the degree to which individual family members are willing to accept the diagnosis. However, Adams et al. (2008) exploring the perceptions of caregiving in relation to multiple family members, suggest that discrete and individual actions of caregiving are often obscured. Purves (2010) further argues that whilst previous studies have served to inform our understanding of the ways in which individual family members have negotiated the perceived changes associated with dementia, there is little evidence as to the interactional experiences between family members undertaking their caregiving roles.

With regard to gender, Paoletti (2001) has concentrated on the imbalance between men and women in relation to caregiving, describes it as a central aspect of gender identification. Highlighting in her critique of the psychological perspective of caring as the category through which one sex is differentiated from the other. Caring, she argues, is *"given"* to women, becoming the defining characteristic of their self-identity and their life's work. Researchers such as Calasanti and Bowen (2006); Campbell and Carroll (2007) suggest that this viewpoint emphasises the historical and perceived compulsory altruism bestowed on women by society. Yet, at the same time, caring is perceived as being taken away from men, whereby not caring becomes a defining characteristic of manhood (Paoletti, 2001). Nevertheless, Netto, Jenny and Yap (2009) assert that this view is no longer acceptable, given the evolving roles of caregiving undertaken by both men and women.

Studies which have examined the relationship qualities, particularly between the adult-child-caregiver and their cared-for-parent for example, are linked to increased caregiver depression and compassion fatigue (Adams et al., 2008; Austrom and Hendrie; 1990, Shanley et al., 2011). This is often influenced by caring for their parent, whilst concurrently dealing with other life demands, such as work and other family commitments (Lee et al., 2015). It is also attributed to perceived insecure attachments of the adult child-caregiver in relation to their cared-for-parent, which Crispi, Schiaffino and Berman (1997) suggest is a predictor of poor psychological adjustment. In contrast, Netto, Jenny and Yap (2009) highlight that within perceived secure attachment relationships, whether they are spousal partners or adult children providing care, there is less experiential burden. Particularly associated with mother-daughter dyads, where existing close relationships were reported as having a more satisfactory response by the caregivers. Although Featherstonhaugh et al. (2017) report that the closer the care dyad relationship is prior to the onset of dementia, there are beneficial outcomes for the cared-for-person. Nevertheless, sixty to seventy per cent of all unpaid caregivers caring for a family member are female (Alzheimer's Society, 2015).

However, Tronto (1993) argues that interpersonal relationships provide the context within which care is both provided and received, suggesting that:

> Throughout our lives, all of us go through varying degrees of dependence and interdependence (ibid: 1993).

In her writing, Tronto further encourages the focus to be related to values rather than gender differentiation, by defining caregiving as a species activity. She argues that this is symbolic of everything we do to maintain continuity and to repair our lived-world experience, in order to live as well as possible. Evidence of this cross gender activity is seen in the growing number of men in the Western world who are assuming the role of spousal caregiver. This is due to the fact that life expectancy is increasing at a faster rate for men than for women (Ducharme et al., 2011). Subsequently, the improved survival of male spousal partners now means that there are increasing numbers of men undertaking the caregiving role (Peacock et al., 2014). However, this can result in a devastating emotional cost, especially with regard to male caregivers (Richardson, 2010). All too often they see their contact with friends diminish and are also deprived of their principal source of emotional support, namely provided by their spousal partners. Researchers such as Arber and Ginn

(1989) refer to these men as the *"forgotten carers"*, or as Barnes et al., (1991) suggest, "*prisoners of love*".

Whether people carry out their caring role in an overt manner, or are hidden and out of sight from the rest of the family and the community in which they live, Braun et al., (2009) highlight that the majority of spousal caregivers for example, are usually the same age as the person with dementia. However, little is known of the caregiving tasks performed by caregiving husbands, as the majority of empirical knowledge undertaken from a feminist perspective reflects almost exclusively the experience of carer-wives (Ducharme et al., 2006). Although research relating to the ambiguity of dementia caregiving undertaken by researchers such as Gillies (2011) and Boss (1993) outline the experience of caring for a family member necessitates a unique type of commitment by the caregiver, in order to maintain their overall personal identity, their experiential sense of *'self'* and *'being'*.

2.4 Being, Self and the Bonds of Attachment

> The main function of *'self'* is to reach out to its world, to internally organise in an appropriate form given the nature of its ongoing experience, and to predict the outcomes of future relational exchanges (Sills, 2009: 56).

In this next section I move the discussion from the generic and externally perceived role of caregiving in relation to policy, academic research and literature, to the internalised and indexical perceptions of being and self, and the bonds of attachment that individuals create with others.

2.4.1 Being "I" Within Our Lived-World Experience

From a hermeneutic phenomenological perspective of interpretation, which is pertinent to this study, the German philosopher Martin Heidegger in his book: *Being and Time* (1962) argues that having the power of sensory perception and conscious thought implies a quality of *'being'* and therefore the presence of something. Reflecting on this, he questions why there is *"something as opposed to nothing"* (1962: 83). Nearly four decades later, the psychologist Franklyn Sills (2009) offers a more direct argument from a psychotherapeutic viewpoint by stating that at the heart of our experience of life there is a basic *'being'* and *'selfhood'*, which he advocates as: *"a locus or*

coalescence, of awareness and meaning, the still centre in the midst of self-conditions" (ibid: 7). He suggests that we *'feel'* ourselves being and possess a sense of *'I-am';* which he purports is the intrinsic factor to our fundamental understanding of our life. However, he proposes that further inquiry as to the nature of being is comparable to a futile attempt at grasping flowing water and suggests that:

> As you immerse yourself in water, you sense its supportive nature. You perceive its presence, you sense temperature, motion, and fluidity; yet its true nature is difficult to describe and even more difficult to define (ibid: 25).

Being (the: *'I-am'* source), he argues is very much akin to this and, as such, is possibly an unfathomable mystery. Nevertheless, Heidegger claims that *'being'* can only be comprehended within the context of time and influenced by the nuances of personal, as well as familial and cultural connotations. It [*being*] cannot be separated from the context of history and relationships. It is not confined within a chronological passing of experiential understanding, but is a process which manifests a particular and personal way of being, encompassing all of our past, present and potential future understanding of the world. Therefore, appearance and reality of life means different things to different people and exists as an inter-being with our psyche within a wider context of the world which we inhabit. Heidegger uses the German term *'Dasein' (da:zan),* which means actuality or presence to define this process *'being'*. He further suggests that we must have Dasein to contextualise and comprehend the world, which is a pivotal and interactive relationship with the *'I-am source'* of being, as well as the *'I-am-this'* experience of self (Heidegger, 1962).

This resonates with the description of lived-experience as offered by the hermeneutic phenomenologist van Manen (1990) in his book *Researching Lived Experience,* in which he succinctly describes four existentials of being. By existentials he refers to the relationship of human existence in response to [our] experience within our lived-worlds. Firstly, *'spatiality'*, the space in which we find ourselves. Secondly, *'relationality'*, the *'lived other'*. This he suggests as being the interpersonal space we share with others. The third existential definition *'corporeality'* is interrelated to the other aspects of our lived-experience and interpretive encounters with others. The fourth aspect van Manen outlines in relation to being is the *'temporality'* of time; of being in the world, appertaining to the speeding up and slowing down of time in parallel with our emotions

and in response to our experiences. He asserts that *"The temporal dimensions of past, present and future constitute the horizons of a person's temporal landscape"* (ibid: 104). He further emphasises that the personal and emotional understanding of our previous experiences reflects on our sense of being as:

> Whatever [I] have encountered in my past now sticks with [me] as memories or as (near) forgotten experiences that somehow leave their traces on my being – the way I carry myself (hopeful or confident, defeated or worn-out), the gestures I have adopted and made my own (from my mother, father, teacher, friend), the words I speak and the language that ties me to me past (family) and so forth (ibid: 104).

Given the features of caregiving with the dementia care landscape, I argue that existential definitions of being, particularly the '*temporality'* of time are extremely pertinent to the sense of self of family caregivers, experienced throughout their caregiving journey.

2.4.2 Territories of the Self

Anthony Elliott, writing from a social science viewpoint, defines self as perhaps being *"the mediator between mind and matter, the interweaving of our internal and external worlds"* (2014: 53). He further argues that for most of us we possess some sense of awareness in relation to the roles which we perform during our day-to-day interactions with others. From differing theoretical and spiritual perspectives the theory relating to the variant constellations of self has been much debated. Whether it be *The Presentation of Self in Everyday Life* (Goffman, 1959); *The Undiscovered Self* of Jung (1957): *The Divided Self* of Laing (1959); self-actualisation with the field of counselling (Rogers, 1959); the relational experience of a: *'true-self'*; *'false-self'*; *'healthy-self'* and *'unhealthy-self'*, as argued by Winnicott (1953, 1969); or the *'paradox of self'* as professed within Eastern religious philosophies such as Buddhism and Sufism.[7] However, there are parallel paths of interpretation within some of these perspectives. For example, Fairbairn's psychoanalytic examination in his selected writings: *From Instinct to Self* (1994a, 1994b) is in

[7] Sufism is described, although much debated, as the mystical side of Islam. However, part of Sufi practice involves meditation and the transformation of self through acts of a direct connection to God.

fundamental agreement with the philosophical argument of Heidegger, in asserting that the experience of self can only be derived from our relationship with others. Sills summarises these similar tracks of interpretation by stating:

> The developing sense of *'being'* is dependent upon at least one essential other who functions as an empathic touchstone (2009: 36).

The concept of self within dementia-specific research has been largely considered from the perspective of the person with dementia (Caddell and Clare, 2011; Hughes, Louw, and Sabat, 2006; Sabat, 2001; Sabat and Harré, 2008). The sense of self, Li and Orleans (2002) argue, is the self of the present and a self that can be:

> Relatively free, free of the worries of mundane life, free of the agony of manipulating complex relationships, free of conformity and convention (ibid: 241-242).

With regard to dementia caregiving, Steven Sabat undertaking a qualitative and longitudinal case study spanning a three year time period involving email communication with one female caregiver, reports a *"flourishing of the self while caregiving"* (2010: 81). During this period, the participant was caring for her husband with dementia. The perception of self experienced by the study participant, Sabat argues, is attributed to the introduction of educational, counselling and psychosocial support to assist her in overcoming her initial feelings of helplessness and low self-esteem. In her auto-biographical account of caring for her mother-in-law who had dementia, as well as also caring for father-in-law, Andrea Gillies (2009) highlights her perception of self and her perceived failure in having to accept the option of relinquishing her role of caring for her in-laws when they entered permanent residential care:

> I think of my state of mind as failure: looking after aging parents is a normal fact of life for millions of people, after all. And it's the right thing to do. It's impossible to argue otherwise. Life has a circular shape (ibid: 236).

Recent descriptive and qualitative research involving twenty family caregivers caring for a relative with Alzheimer's disease undertaken by Skaalvik et al., (2016) examines participants' sense of self. Utilising Harré's (1998) social constructionist theory of selfhood in the identification of expressions of selfhood, the authors report that study participants expressed challenges to their

personal attributes, relations and positioning. Peacock et al., (2014, 2016) in an interpretive descriptive study highlight the notion of *'reclaiming self'* experienced by ten bereaved spousal caregivers. The authors report that the features and facilitators of the post-bereavement experience require the participants' recognition and acknowledgement of their sense of self, prior to, during and post caregiving. However, in the reviewing of dementia related literature I note that there still remains a scarcity of discursive research relating to the caregivers' sense of self and attachment to others during their entire caregiving journey.

2.4.3 Foundational Bonds of Attachment

Bereavement literature, such as research undertaken by Colin Murray Parkes, suggests that as human beings we are unique from other species, in being able to construct internal worlds to interpret the complexity and magnitude of our perceived reality. Drawing on child psychology for example, his terminology of an *'assumptive world'* is the child's internal model regarding interpretive assumptions in relational attachment with the parent. However, he further argues that not only as children, but also as adults our assumptive world is:

> Our most valuable piece of mental equipment; without it we are literally lost (2006: 31).

Parkes progresses this argument further by highlighting that our assumptive world is not fixed, but is constantly being reviewed. The decisions we make are achieved in relation to supplementing, or contradicting assumptions previously made by us within our experiential view of the temporality of our reality. In tandem with this he also contends that there are other internal models, highlighting the feared and anticipated hoped-for-worlds, from which we come to view our experiences.

From a psychotherapy and counselling perspective, Marla Arvay (2001) states that an individual's view of the world is essentially a subjective experience, emphasising that the nature of reality is formulated in both individual and collective constructions. She further asserts that:

> Knowledge and truth are not discovered, but are created or invented. In the end every person's world is unique to them even when it reflects a shared environment (ibid: 215-216).

Our shared *'lived-world'* experiences of self are undertaken through our interpretation of our perceived reality with others. In doing so we form inter-relational attachments throughout the duration of our lives and within the navigated environments in which we traverse. Prior to exploring the landmarks of grief, loss and bereavement within the landscape of care, consideration must be given to a distinct feature of the natural world; this being the concept of attachment. With regard to human interactions, attachment theory for example, offers us a way to conceptualise the propensity in human beings to create and sustain strong bonds of affection with others. Enabling us to interpret and react to events when these bonds are perceived to be threatened, or indeed broken (Bowlby, 1969, 1973, 1980; Wilson, 2014; Worden, 1991).

The vision of attachment as outlined by Bowlby, for example, spans the theoretical continents of cognitive psychology, neurophysiology and developmental biology. In his writings Bowlby purports that these arise from a need for security and safety, which are developed early in life and directed towards a few specific individuals. Researchers such as Engelhardt (2012) and Hooper (2007a, 2007b) highlight the concept of the emotionally *'parentified'* child whereby a parent, in order to overcome possible deficits of attachment issues within their own childhood, continuously seeks emotional and/or psychological support from their own child. Hooper (2007b) asserts that the provision of support is often undertaken by the child without experiencing reciprocity of care from their parent in return.

Within the field of social science the forming attachments with significant others is considered normal, not only for children, but also for adults. This attachment behaviour is a dominant feature, especially in times of ill-health and loss (Bowlby, 1969). Attachments become the bonds of human interaction which often tie individuals together from birth to death and emotionally, even beyond. A number of research studies have examined attachment in relation to dementia (Cooper et al., 2008, 2009; Crispi et al., 1997; Kjällman et al., 2013), citing experiential anxiety and avoidance being associated with lower caregiver wellbeing. In a dementia related study involving individual semi-structured interviews undertaken with 15 mother-adult daughter dyads, Ward-Griffin et al. (2007) report differing dynamic relationships. They highlight *custodial* and *cooperative* experiences within caregiving, which relate to the provision and receipt of care within a cohesive and cooperative relationship. In contrast, the researchers also cite experiences which are perceived

by mother-adult daughter dyads as being emotionally focused relationships, which are experienced as being *custodial* and *combative*. Although Sills (2009) furthering the discussion of attachment theory, considered to be prominent within the field of inter-disciplinary social sciences, states that there is often a mis-interpretative approach in tracing the origins of the human condition, self and selfhood. Yet he considers that attachment is an important relational interchange, being an outer expression of our inner world(s) and the development of a self-system of analysis of our everyday day-to-day life.

2.4.4 Continuing Bonds Across the Dementia Care Landscape

The notion of the continuation of bonds is generally interpreted in the social scientific community as denoting the presence of an ongoing inner relationship with the deceased person, undertaken by the bereaved individual (Richardson, 2010). However, for many family caregivers there is, and indeed in some cases without choice, a continuing bond within the caregiver/care-recipient relationship. However, research such as the work of Sweeting and Gilhooly (1997) define this as living with someone who is perceived to be emotionally or *'socially dead'*. Or the phrase *'death-in-life'* utilised by the clinical psychologist Robert Kastenbaum (1988) to describe Alzheimer's disease and other dementias, or as Woods (1989) contends as coping with a *'living death'*.

From a non-dementia perspective Horowitz (1997) talks with regard to the *'breaking of bonds'* or the *'severing of ties'*; suggesting that the idea underlying the use of such phrases, at least in a theoretical context, is not that the deceased needs to or will indeed be forgotten. Rather, the bereaved person must come to realise that on some level an irrevocable separation has taken place and that the person cannot be brought back. Although Sills (2009) suggest that when a person expresses that someone, for example, *'lives on'* in their memory, they are continuing a bonded connection with that person by recognising that it may be possible to externally let go of the person *'out there'* in the world. Whilst conversely, realising that they never lost them *'in here'*, within their internalised world.

Nevertheless, the grief work notion with regard to dementia is the claim that a person has to confront experiences associated with bereavement in order to come to terms with loss and to avoid detrimental health consequences (Peacock et al., 2016; Stroebe and Schut, 2001a). Even though

this basic hypothesis appears reasonably straightforward, a major controversy in bereavement literature has arisen around the question of whether the process and/or purpose of grief work involves letting go of continuing bonds with the deceased person and therefore what leads to healthy adaptation and the overall wellbeing of the remaining person (Austrom and Hendrie, 1990). This is echoed in the writing during the same period by Elizabeth Forsythe (1990), in her book *Alzheimer's disease: The Long Bereavement*; who refers to her profound and painful experience of caring for her husband John, diagnosed with Alzheimer's disease, and his deep withdrawal away from her into unreachable isolation.

2.5 Setting the Scene of Change, Grief and Loss in Dementia Care

> And a woman spoke, saying, tell us of pain. And he said: your pain is the breaking of the shell that encloses your understanding (Gibran, 2013: x).

In part five of this chapter I introduce and discuss the concepts of grief, loss and bereavement in relation to the contours of care within the dementia caregiving journey. Hughes (2008) argues that due to the consequences of organic damage, the cognitive ability of the person with dementia is reduced. Their ability to process information and their interactions with others will change. For some caregivers and for the person with dementia this change may be fairly sudden and discrete, but for most, dementia will rob them of one another in a slow and insidious process. Pringle (2003) highlights that for people living with dementia there may be *'good days'* and *'good moments'*. Yet for many there are also *'bad days'* and days of stupor; thus creating greater ambiguity within the relationship (Boss, 1999). Researchers such as Sweeting and Gilhooly clarify this by stating that the grief experienced by caregivers of people with dementia is often further intensified by *"not knowing whether a loved person is absent or present, dead or alive"* (1997: 4). They further contend that this ambiguous situation presents a state of confusion for caregivers with regard to their status and role within the relationship; which they further argue often leads to the creation of guilt by carers in relation to their grief experience They further assert that the ambiguous nature of the caring role for some caregivers, prior to the death of their family member, may not be fully perceived as feelings of grief. Thus, their experiences may be misconstrued as being symptoms of depression. In addition, the experience of grief for dementia caregivers may also be unrecognised.

From a thanatological perspective, the study of death and dying, Doka (1989, 2014) suggests that there are also experiences of disenfranchised grief, defining this as being those hidden and unidentified sorrows:

> The grief that persons experience when they incur a loss that is not or cannot be openly acknowledged, publicly mourned, or socially supported (Doka, 1989: 4).

This resonates with the often daily experience of the caregiver of metaphorically losing the person with dementia on both a physical and cognitive level, as well as the more personal aspects within the cared-for-person and caregiver relationship. From a grief perspective, not specifically related to dementia, Doka and Martin (2000) suggest in their book *Men Don't Cry… Women Do: Transcending Gender Stereotypes of Grief*, the adherence of two grieving styles. The authors cite *intuitive* and *instrumental* grief as being adaptive processes undertaken by people as an oscillating response to their post-loss world. They go on to describe that people during their grieving process may not necessarily cry, but may employ or engage with activities that help them to overcome their grief. This may include thinking and talking through the event, as well as being argue that many dementia caregivers because of shame, embarrassment, guilt and anger, may feel the need to keep their grief a secret and as such are often reticent in seeking support from other family members or healthcare services.

2.5.1 Defining the Topography of Grief, Loss and Bereavement

Within the field of academic research there are many differential and contradictory definitions relating to grief, loss and bereavement. Wilson (2014) offers a number of helpful delineations from a bereavement counselling perspective with regards to clarifying terminology:

> Bereavement is what happens to you. Grief is what you feel: the affective and cognitive state you are likely to experience following a significant loss (ibid: 27).

He suggests that in contrast to the more public act of mourning, which he argues is often driven by cultural and religious tradition, grief represents the affective and cognitive state experienced after loss. He further suggests that grieving is the process and an activity which is surrendered to in private. Wilson's distinction in relation to grief is further highlighted in the direct interpretation of

the word grief, originating from the Latin word *'gravis'*, meaning heavy. Yet, with particular regard to our Western culture he argues that:

> Experiencing grief often means the loss of something dear to us being violently taken away, resulting in experiential feelings of heaviness and depression (2014: 28).

Seminal grief research undertaken by Therese Rando (1986) suggests that when someone experiences grief, they may feel a sense of loss in their innermost self and thereby experience an accompanying set of emotions and behaviour. These representational emotions and behaviours, Rando argues, are grief manifestations which are the symptomatic features of the grieving process. However, within the field of grief research there are many theoretical frameworks which have been extended by researchers such as Rando (1986, 2000) and Worden (2009) for example, to enable a greater understanding of the contextual and emotional *'stages'* of grief. The most pertinent to my own previous working practice is the work of Elizabeth Kübler-Ross. In her book: *On Death and Dying* (1970), Kübler-Ross outlines the non-linear grief cycle model of the five stages of grief, which she argues that people may or may not experience. Stages which are transferable to varying degrees in response to personal change and emotional upset, resulting from factors other than death and dying.

These stages encompass firstly *'denial'* which is associated with the conscious or unconscious refusal to accept reality. Secondly, *'anger'*, the emotional upset experienced as internalised anger with oneself, or externalised and expressed to others. Thirdly, *'bargaining'*, the undertaking of perceived possible outcomes often associated as negotiated conversations with God. Fourthly, *'depression and isolation'* relating to the experiential emotions of post-loss, as well as accompanying feelings of reality after the event. In addition, *'acceptance'*, a stage-experience in which varying levels of detachment and possible relocation are achieved, predicated on the situation of the individual.

Building on her original work, Kübler-Ross together with her co-researcher and David Kessler in their book, *On Grief and Grieving: Finding the Meaning of Grief through the Five Stages of Loss* (2005), argue that: *"our grief is as individual as our lives"* (ibid: 7). They further assert that these five *'tools'* are the normal grief-stage framework which enable us to identify what we may be

feeling during the grieving process. Nevertheless, they emphasise that these stages are not stops on some linear journey and, more importantly, are not undertaken in any sequential or prescribed order. They further acknowledge that:

> With these stages comes the knowledge of grief's terrain, making us better equipped to cope with life and loss (ibid: 7).

Grieving is something that we perhaps undertake every day, even at some minor level, argues Mary Paula Walsh in her book: *Living After a Death: A Guidebook for the Journey of Bereavement* (1995). She offers a simplistic example which we all may have experienced at some point or another, relating to missing the bus on our daily commute to work. Initially, she suggests we experience shock and then move on to feelings of denial. In doing so, we check our watch and may even ask other people in the queue if indeed the bus has really been and gone. The next step she highlights is our feelings of anger, often directed at the bus company, or perhaps we blame family members for causing us to be late. We may also incur feelings of guilt that being late was actually due to our own behaviour, spending too much time getting out of bed, getting ready or eating breakfast for example. At this point Walsh outlines the possibility that we may participate in acts of bargaining with God such as: *"please let the bus come and I'll reform my life – get up earlier, eat less breakfast"* (ibid: 19). Finally, she suggests that we accept our situation and as our feelings of grief in missing the bus subside, we orientate ourselves back into reality. Thus, we acknowledge that we are late and in doing so we begin to make choices as to how we are actually going to continue on with our journey. Yet for caregivers caring for a family member with dementia the journey towards bereavement is filled with other experiential aspects of grief and loss, which are often unanticipated and ambiguous within their landscape of care.

2.5.2 The Hinterland of the Dementia Caregiving Journey

Perhaps the most relevant model of grief pertinent to dementia care is anticipatory grief. I would argue that this can be considered as being the *'hinterland*' of the dementia journey; the experiential area of the dementia caregiving journey which often lies beyond what is visible or known to others. Author and psychiatrist Erich Lindemann in his paper: *Symptomatology and Management of Acute Grief* (1944) was the first person to proffer the term *'anticipatory grief'*. Referring to grieving that

he perceives to occur prior to the actual loss. Researchers suggest that this form of grief for dementia caregivers probably begins when the behaviour of their family member alters sufficiently to create the need for change in the everyday life of the family (Adams and Sanders, 2004; Adams, 2006; Blandin and Pepin, 2015). However, the majority of research undertaken relating to anticipatory grief in dementia care has utilised the application of quantitative tools, such as the Meuser-Marwit Caregiver Grief Inventory (MM-CGI; Marwit and Meuser, 2002, 2005). These studies do not offer specific in-depth qualitative research data and are therefore not pertinent to this research study.

Following on from Lindemann's conceptualisation of anticipatory grief, Rando (1986) suggests that anticipatory grief cannot be assumed to be present merely because of a warning, or of a terminal illness diagnosis being given. She argues that it is not, as Lindemann initially suggested, post-death grief begun early. Asserting that in reality there are, in fact, three time foci in which anticipatory grief directs itself, being the past, present and future. The mourning/grieving, whether publically or privately, of past losses and experiences, stimulate and has an impact on an individual's life and losses not only occurring in the past and the present, but also the future. She offers the definition of anticipatory grief as being:

> …the phenomenon encompassing the processes of mourning, coping interaction, planning and psychological reorganisation that are stimulated and begun in part in response to the impending loss of a family member and the recognition of associated losses in the past, present and future. It is seldom explicitly recognised, but the truly therapeutic experience of anticipatory grief mandates a delicate balance among the mutually conflicting demands of simultaneously *holding on to*, *letting go of* and *drawing closer* to the dying patient (1986: 24).

Although in relation to dementia the acceptance of a family member's death, occurring socially or otherwise while he or she is still alive, may leave the caregiver feeling that the person with dementia has been abandoned. For some, expecting the loss often makes the attachment to the person with dementia stronger. Anticipatory grief involves a series of grieving episodes in which the significance of an anticipated loss (the loss of the person) is considered and reconsidered. Fulton and Fulton (1971) and Fulton and Gottesman (1980) offer a theoretical framework comprising three levels of analysis in relation to anticipatory grief.

This multi-dimensional level of analysis comprises the psychological level, relating to the coping abilities, beliefs, feelings and psychological characteristics of the bereaved; the overall emotional aspects of grieving, as outlined by Kübler-Ross (1970) and Kübler-Ross and Kessler (2005). In addition, Fulton and Gottesman define an interpersonal level, relating to the type of relationship being grieved, the style of responding to the situation and the type of support the person receives. This is the *'pebble in the pond'* effect of caring and grieving as suggested by Rando (1986: 64). Finally, the social-cultural level is associated with the norms, roles and rituals available to the bereaved in beginning to sever the physical ties of the relational bonds of attachment with the deceased person. Fulton and Gottesman (1980) highlight this final level as being associated with forward planning, in particular with regard to the funereal aspects of bereavement. Although in relation to dementia care, this third level also incorporates the transitionary periods relating to the re-adjustment and response to losses experienced by caregivers on their dementia journey and echoes those oft spoken clichés expressed by caregivers, relating to the ambiguity of *"living with and without"* the person with dementia.

From qualitative research Boss (1999) developed the concept of ambiguous loss, a theoretical framework used to understand the grief and loss in caregivers of people with dementia. She states that the grief of the caregiver is compounded by *"not knowing whether a loved person is absent or present, dead or alive"* (ibid: 4). Boss argues that this situation, the "*goodbye without leaving*", creates confusion for caregivers about the roles and status within their relationships. Added to this, caregivers may also have a sense of guilt relating to their feelings of grief for the experienced losses within their lives. Some spousal caregivers for example may be able to adjust to this ambiguity, this unpredictability and be able to redefine what it means to be a couple, thus enabling them to maintain a sense of *'couple-hood'* (Hellström, Nolan and Lundh, 2007; Kaplan, 2001). An example of this is where spousal caregivers preserve a continuity of caregiving for their family member, even when the person with dementia has left the family home and has moved into a permanent residential care setting. Kaplan (2001) highlights that the continuum of couplehood is attributed to the sense of belonging by the caregiver spouse in terms of their relationship with the cared-for-person.

With regard to healthy adaptation and adjustment, Stroebe and Schut (2001) and Richardson (2010) suggest a dual process model. They purport two key issues of experiential oscillation between *'loss orientation'* and *'restoration orientation',* which are applicable to anticipatory grief in relation to dementia care. It involves the vacillating transitional task of living with and within the relationship, to living without it. They suggest that loss orientation may be the mourning and the searching, consciously or subconsciously, of what has been and what can possibly never be the same again. The term restoration orientation describes strategies which caregivers of people with dementia apply in an attempt to retrieve a sense of normality within their everyday life.

2.6 Review of Chapter Two

It is through the lens of academic research and policy documentation that I have reviewed and synthesised relevant research literature, by initially exploring the development of policy in relation to dementia care. I have then progressed to the role of family caregivers, as well as offering the differentiated experiences of spousal and adult caregiving children caring for a family member within current literature. In addition, I have also discussed the aspects of caregiving from a gender-related perspective. Narrowing this discussion further, I have addressed the psychological and interpersonal levels of self, being and attachment. Finally, I introduced the concepts of experiential grief, loss and bereavement in relation to the contours of care within the dementia caregiving journey. In the next chapter, chapter three, I move on to discuss the methodological approach undertaken in relation to this research study.

Chapter Three

The Methodological Approach to the Research Journey

3.0 Introduction

This chapter is divided into seven parts. Part one begins with my anticipated perspective in undertaking this research journey and a repetition of the aim of this study. Presented in part two is a review with regard to the qualitative methodological routes considered, although not undertaken and an explanation as to my reasons why. Part three outlines the methodological route and an explanation as to why this particular route was chosen. In part four I discuss the design of this research study, outlining the overall '*mapping out*' as to the recruitment of a convenience sample of thirty study participants and the semi-structured interview process. In addition, I offer a brief synopsis relating to each of the participants involved with this research study.

Part five of this chapter outlines a step-by-step approach in the adaptation and application of the theoretical framework of anticipatory grief and loss by Fulton and Fulton (1971) and Fulton and Gottesman (1980), which enables the analysis and reconceptualisation of data relating to the interpretative experience of study participants within a tri-dimensional layered landscape. Particularly the emergence of a conceptual framework which intersects with this landscape and relates to participants' fluctuating perceptions of self in response to their experience of change, loss and bereavement during the course of their caregiving journey.

In part six, the penultimate section of this chapter, I offer a reflective view with accompanying excerpts from my reflective diary which highlights my location and orientation within the research landscape. Also discussed in this section of the chapter is my experiential narrative of dementia, grief, loss and bereavement which paralleled this research journey. Part seven is a review of this chapter.

3.1 The Reason for Undertaking this Research Journey

> The traveller must first find in himself a good and sufficient reason for going… Next he must plan his trip in time and space, choose a direction and a destination. And last he must implement the journey. How to go, what to take, how long to stay. This part of the process is invariable and immortal. I set it down only so that newcomers … will not think they invented it. (Steinbeck, 1962: 3-4)

As previously discussed in chapter one of this document, there is to date a paucity of research exploring family caregivers' experiences of sense of self in relation to change, grief and loss across the entire dementia care-giving journey. This is the fundamental reason why I chose this topic of research, to begin to redress the gap in existing knowledge and understanding of the lived-experience of family caregivers.

Having previously read, some years ago, John Steinbeck's book *Travels with Charley in Search of America*[8], the quotation resonated with my anticipated outlook as to the necessary requirements of planning and carrying out my research journey. I did wonder if other researchers felt this way in relation to their research experiences, or whether it was just me who had pre-research feelings of apprehension. As with all journeys that I have undertaken, whether they have been physical or cognitive, I began by asking myself numerous reflexive questions. These questions related to what would be: "*my starting point?"*; "*which methodological and theoretical route should I take in order to elucidate robust data?";* "w*ho would I involve as study participants*?" and anticipating what would perhaps be "*my journey's end?"*

It was comforting to read that other researchers had also experienced feelings of apprehension as to how to undertake their research. Although professionally my background is not within the field of nursing, I was reasurred by Cohen, Kahn and Steeves, writing in their book *Hermeneutic Phenomenological Research: A Practical Guide for Nurse Researchers*, who also cited the same Steinbeck quotation in their introductory chapter "*getting started*" (2000: 2). With this duplication of expression I felt somewhat reasurred that perhaps I was "*on the right track"*. Well at least in

[8] '*Charley'* was the name of John Steinbeck's travelling companion, a ten year old standard poodle.

thinking ahead to perhaps what my journey, my research journey, *"would", "should"* and "*could*" entail in addressing the aim of this research study relating to:

> the exploration, in part retrospectively, of the complex and emotional aspects of the fluctuating perceptions of self experienced by thirty family caregivers in response to change, grief, loss and bereavement during their entire dementia caregiving journey.

What was also required was my "*direction*" in choosing the appropriate methodological route which would enable me to empathically interpret the landscape of caregiving relating to the perspectives of study participants. However, what transpired during the course of this study not only highlights a complex journey, but also the emergence of a concept of three interconnected fluctuating perceptions of self experienced by participants and myself.

3.2 Methodological Routes Considered

During the course of my research I was repeatedly drawn back to Steinbeck's quotation and the importance of "*planning one's journey"*. I had "*sufficient reason for going*", this being my research aim and so my next step was to choose my "*direction*". I identified this as being my methodological approach. Choosing the appropriate methodology I felt would be the navigational tool for my research and the subsequent generation of in-depth research data. The sections below outline my exploration, discussion and final decision relating to the qualitative methodological route I felt to be the most appropriate in carrying out this research study.

During my previous academic research, undertaken for my MSc dissertation relating to dementia, anticipatory grief and loss of older male spousal carers, I had employed a hermeneutic phenomenological approach. However, given the emotive topic, as well as the envisaged complexity and involvement of a much larger participant research group, I felt it was necessary to explore other qualitative approaches to ensure appropriateness to the overall aim of this research study. In addition, I also considered that this would enable me to further develop my academic skills in relation to research.

Increasingly, the media, human service professionals and social researchers attain their information about society by means of qualitative interviews. Denzin and Lincoln (2002) argue that an interview is not to be considered as an information gathering tool per se, it is not a commodity that you hire someone to collect for you, or that you pay someone to give you, but that [it] belongs to a moral community. To further clarify this point they cite a topographical analogy taken from a quotation by Aldo Leopold which states:

> We abuse land because we regard it as a commodity belonging to us. When we see land as a community to which we belong, we may begin to use it with love and respect. We do not own the land; the land is a community to which we belong (Leopold, 1949: viii)

Denzin and Lincoln (2000) further request that we, the researcher and readers, substitute the words "*interview*" and "*research*" for the word "*land*" as we all, he suggests, [should] belong to a moral community. They argue that interviews must be viewed as being a privilege granted to us, not as a right that we perceive that we possess. In doing so they argue that interviews are not things that belong to us, but are part of the conversational dialogues connecting all of us to this larger moral community and operating as the transformation of information into a shared experience. Guidance as to the consideration of my methodological approach was further offered by researchers such as: Boyd (1993); Crotty (2015); Denzin and Lincoln (2000), who list not only phenomenology and hermeneutic phenomenology, but also grounded theory and narrative research as being potential methods from the qualitative tradition. Beginning with the latter two, these methodological routes were therefore considered.

3.2.1 Grounded Theory Research

Backman and Kyngäs (1999) highlight that the researcher undertaking a grounded theory approach should identify and suspend pre-existing knowledge of the research topic. They should '*bracket off'* their previous experience and approach the data without prejudice or bias. In contrast, Baker, Wuest and Noerager, (2006) offer a counter argument stating that former knowledge enables the researcher to further observe and understand the research process. Nevertheless, I felt that given my work-related and previous academic experience I was totally embedded within the landscape of dementia care. Having already considered the issues I wished to address in undertaking this

research study, I therefore turned my attention to narrative research as being a possible methodological option.

3.2.2 Narrative Research

Researchers such as Murray (2015, 1999) and Sarbin (1986) highlight that the application of a narrative theoretical approach to research enables the researcher to enter into the life-story and storied-world, the actual day-to-day lived-experiences of the research participant. Murray (2015); Smith, Flowers and Larkin, (2009) assert that narrative research encourages participants, through the interview process, to offer extended accounts of their lives and sense of selfhood. From an application based perspective this methodological approach was initially appealing in my anticipation of being able to generate personalised in-depth data. However, as Creswell (2007) highlights, narrative research involves a small number of research participants and my rejection of this particular approach related to two concerns. Firstly, the involvement of a small cohort of participants I felt would not elucidate a broader understanding of the experiences of caregivers in relation to the aim of my research. Secondly, and perhaps more importantly, given the emotive and complex nature of the topic, I did not wish to intrude into the lives of the study participants more than was actually necessary. Therefore, I returned to the more familiar path of phenomenology.

3.2.3 Exploring the Phenomenological Path

Fortune and Reid, (1998) suggest that the application of a phenomenological approach to research is thought to be effective for generating descriptive data on complex issues, such as relational dynamics and their influences. Whilst Grbich (2007) argues that phenomenology is an approach which enables the researcher to understand the hidden meanings of experience. Distilling this further, van Manen (1990) offers a concise, although perhaps rather confusing, one-word definition in stating that phenomenological research is the study of "*essence*" of the existentials of experience. Although this definition is philosophically succinct and appropriate, I feel, before moving on, that clarity must be offered as to the question of "*what exactly is phenomenology*?"

From a linguistic perspective, the term '*phenomenology*' is derived from the Greek word '*phainomenon*', meaning 'appearance' or phenomenon (Hughes, Louw and Sabat, 2006;

Laverty, 2003). Considered as a branch of metaphysics, it is the study of appearances as opposed to reality and as such is distantly related to the epistemological doctrine of '*phenomenalism*'. This doctrine purports the theory that physical objects do not exist as things in themselves, but only as perceptual phenomena or bundles of sense-data situated within the temporality and spatiality of our lived-world experience. However distinct, it may be perceived as being an individual philosophical discipline, or as a movement bound within the history of philosophy per se. Hughes et al. (2006) argue that phenomenology, the study of structures of consciousness (*how we think in relation to our experiences*), is closely related to other key fields within philosophy. Citing the core fields of philosophy being: ontology - the study of beings or their being (*what is*); the area of epistemology - the study of knowledge (*how we know*); ethics - the study of right and wrong (how we should act); and logic appertaining to the study of valid reasoning (*how we should think*).

From a dementia-related disciplinary perspective, Hughes et al. (2006) further suggest that phenomenology is an approach that encourages understanding. Compelling us to reflect further on the importance of contextual relationships as a means to enable us to embrace and interpret the experiential meanings of others. Essentially, being the study of *'phenomena'*, which Hughes and colleagues define as being akin to a philosophical calculus of interpretation in relation to: the appearances of things; or things as they appear in our experience; or the ways we experience things. Thus, the meaning of things we have in our experience as a whole. The sum of which is a study of the conscious processes as experienced from the subjective *'I'*, which offers an individual first-person point of view.

However, phenomenology is not without its critics. The cognitive scientist David Dennett (1991) argues that given the explicit first-person approach it is therefore incompatible with the scientific third-person perspective. In addition, relating to the field of the philosophy of language, the social philosopher John R. Searle (2008) has commented on what he refers to as the '*phenomenological illusion'*. He purports that with particular reference to the relational aspect of what is '*not phenomenologically present'* is therefore not real and conversely, that which is '*phenomenologically present'* is therefore in fact an adequate description of how things really are and are ultimately experienced. However, I found this to be a simplistic and quixotic explanation. This may be viewed as a precocious statement, but Searle's illusionary depiction of

phenomenology did not resonate with either my aforementioned '*real-world'* working practice, or with my research experience. My previous academic and practice relationships with family caregivers of people with dementia have informed my view as to the fact that the "*lived-experiences'* of caregivers are often topographically hidden beneath the surface and therefore are all too often not visibly apparent. These '*experiences*' as Hughes et al., (2006) suggest are related to the universal features of discursiveness, spatiality and our individualised sense of self. Applying this to the day-to-day language of the aspects of dementia care spoken about by family caregivers, I argue that it is often the intersubjectivity of the unspoken, the silences and accompanying body language which actually present how reality is perceived by the person.

Therefore, I envisaged that a phenomenological approach [would] elicit these hidden facets of experience of the research participants. I also found myself in agreement with Denzin and Lincoln (2000), who perceive that a phenomenological research relationship is between the investigator (researcher/myself), whom they view as being a '*passionate participant*', working with the investigated (research participant) in the co-creation of findings. I felt that utilising an interpretivist approach, such as phenomenology, would therefore enable both the participants and myself to transcend the boundaries between textual, spoken and indeed unspoken language. This would enhance a holistic depiction and understanding of their *"lived-world"* experiences rooted across the landscape of their dementia caregiving experience. Laverty (2003) highlights our understanding of phenomenology and the further development of hermeneutic phenomenology as not relating to stationary concepts, but that it is dynamic and therefore ontologically evolving. However, in order to gain a firm theoretical footing in relation to the foundational and comprehensive concepts of phenomenology, we need to take a step back to the latter half of the 19th century and to the beginning of the historical movement of phenomenology itself.

3.3 Returning to Gadamer

Originally associated with the work of such philosophers as Wilhelm Dilthey (1833-1911), the launch and development of phenomenology as a modern philosophical tradition did not occur until the first half of the 20th century and was originated by the eminent philosopher and often referred to as the '*father of phenomenology'*, Edmund Husserl (Koch, 1996). Husserl's academic work was

initially related to empirical research, exploring the calculus of variations within the natural sciences. However, Husserl changed his directional research interests towards a more philosophical approach in the pursuit of finding a universal foundation between both philosophy and science. This culminated in his developmental exploration and elucidation of the contextual aspects of phenomena: the "*being of"* and the "*lived-world*" which encompass the taken-for-granted human experience of the life that we lead (Smith, Flowers and Larkin, 2009; van Manen, 1997).

Throughout his research Husserl sought a deeper understanding of the experience of reality and the study of phenomena as they appeared through human consciousness. Both Husserl, and later Heidegger, began to move away from the scientific view of the world, based on Cartesian Dualism as epitomised in the much cited quotation of René Descartes: *"cogito ergo sum", "I reflect therefore I am".* In doing so, they argued the existence of the heuristic experience of being as present in not just "*one-life-world"*, but "*many life-worlds"* (Koch, 1995, 1996; Laverty, 2003). Husserl suggested that this is achieved by a co-constituted dialogue between the person and the world (Valle, King and Halling, 1989). In doing so, Husserl chose to emphasise an epistemological perspective relating to the relationship between the *'knower'* and the '*object of study'*. Laverty (2003) advocates that albeit the fact that Husserl refrains from utilising a positivist framework of ontology and epistemology, Husserl continued to be strongly influenced by his scientific approach.

This view is highlighted by the hermeneutic phenomenologist Hans Georg Gadamer in his book: *Truth and Method* (1960) who argues:

> In a series of many investigations he [Husserl] attempted to throw light on the one-sidedness of the scientific idealisation of experience....To me, however, he still seems dominated by the one-sidedness that he criticizes, for he projects the idealized world of exact scientific experience into the original experience of the world, in that he makes perception, as something directed toward merely external physical appearances, the basis of all other experience (ibid: 347).

My departure from a deductive phenomenological approach was because of this scientific idealisation, essentially the pursuit of objectivity and neutrality, in particular associated with the key concept of Husserlian reduction or '*bracketing'*. Cohen and Omery (200, 1994) and Paley (1997), define the metaphor of bracketing as the unpacking of phenomena, whereby the

researcher's subjective perception is '*bracketed off'* from the phenomenon experienced by the research participant. Enabling the researcher to examine and analyse symbolic meaning in its purest form. Koch (1995) asserts that rigour within research, namely reliability and validity of our interpretation and subsequent understanding of the experiences of others is paramount. She highlights that within phenomenological research it is the bracketing off of our pre-conceptual understanding, with the intentional focusing being on the experience of the participant which is central to the rigour of the study.

Conversely, within hermeneutic phenomenology, Koch further (1995) argues that the pre-conceptual understanding of the researcher remains, but that there are stages of interpretation that allow patterns to emerge. What is critical is how the discussions arising from the data are achieved, together with the interpretive processes, which are important in the elucidation of understanding. I knew that from a personal, as well as a professional viewpoint, given my work-related experience, that the putting aside of my own subjective pre-conceptions would be extremely difficult. I therefore concur with Gadamer (1960), who advocates from an inductive approach, that all understanding is dependent upon our pre-understanding in the co-creation of the '*life-world'* experience of the researcher and participant. Creswell (2007) argue that unlike the deductive researcher, a researcher utilising an inductive approach works from the "*bottom-up, using the participants' views to build broader themes and to generate a theory interconnecting the themes*" (ibid: 23). I therefore chose to return to a hermeneutic phenomenological path of enquiry and interpretation which I had previously used in my MSc research study.

As previously discussed, hermeneutic phenomenology is associated with the pre-conditions of understanding, as outlined by Heidegger (1927); which was further developed and more pertinent to this study, by his student Gadamer (1960). As with phenomenology, the term hermeneutic derives from the Greek language and the word '*hermeneusis*', meaning, in particular, the interpretation of messages and texts (Laverty, 2003; Widdershoven and Berghmans, 2006). Therefore, understanding from a hermeneutic phenomenological perspective is the contextualisation and re-contextualisation of any individual item (information process or experience), or as Schwartz and Wiggins (2004) suggest "…*by grasping its meaningful placement within and the subsequent relatedness to other items that form the same context"* (ibid: 355).

From my own work-practice and personal experience, I concur with Hughes et al. (2006) who further contend that: "*Grasping meaning involves a lot more than might be suggested by simple algorithmic accounts of language function"* (ibid: 39). Geanellos (1998) advocates that to engage in hermeneutic phenomenological dialogue with research participants, a researcher must first review their own fore-structures of understanding as outlined by Heidegger. The three-fold format of the fore-structures of understanding relate to: '*fore-having', 'fore-sight'* and *'fore-conception'*, collectively being my acknowledgement of [my] prejudices or pre-understanding, which he argues are the necessary prerequisite conditions in relation to the interpretation of the narratives of research participants. A personalised adaptation of my fore-structures of understanding vis-à-vis the participants involved in this particular research study is outlined in Table 2.

Table 2 Fore-structures of Understanding

A personalised adaptation of Heidegger's fore-structures of understanding	
Fore-having	I, as researcher, come with a practical familiarity which thus makes interpretation possible – [my Alzheimer's Society experience of working with people living with dementia, as well as my academic research, and my personal experiences of caregiving, change, loss and bereavement].
Fore-sight	Because of my [historical] background I have a point of view – [thus can make an interpretation with regard to the research topic].
Fore-conception	Given my background I may have some expectations – [which may/may not influence my interpretation of the research data].

3.3.1 Thresholds, Circles and the Fusion of Horizons

Academic writers such as Geertz (1973) and Grbich (2007) suggest that a hermeneutic phenomenologist researcher examines how the world is experienced by others and what people may imagine that world to be. In addition, the phenomenologist researcher should therefore attempt to gain entry into the conceptual world of the people they are working with, in order to

understand the '*how*' and '*what*' meanings they may construct around events in their daily lives. Boyd (1993) and Finlay (2002) further argue that a phenomenological approach to research is utilised to describe the meaning of the "*lived-experience*" of the individual, which refers to the focus on human behaviour in the context of the relationships to things, people, events and situations. Entering into the lived-experience of each individual participant, I envisaged that during this research journey my pre-conceptions may be challenged. In essence, that in undertaking this journey and crossing the '*threshold*' into the "*lived-world*" of participants, I too would undergo experiences of transformative learning in relation to dementia care. From a pedagogical perspective, researchers such as Elias (1997) define this experience of transformative learning as:

> An expansion of consciousness through the transformation of basic worldview and specific capacities of the self (ibid: 3).

Developing this further Mezirow (1998) purports that transformative learning signifies a key route to the development of critical thinking. Other researchers such as Cousins (2006) and Meyer and Land (2003) highlight that transformative learning may prove to be challenging, which often leaves the '*learner*' (myself) in an oscillating state of liminality, between pre-and-post learning. With Palmer (2001) contending that the state of liminality is where the learner crosses the threshold of learning and thus may experience a state in which:

> The truth or insight may be a pleasant awakening or rob one of an illusion; the understanding itself is morally neutral. The quicksilver flash of insight may make one rich or poor in an instant (ibid: 4).

In relation to dementia, Blandin and Pepin, (2015) purport that liminality, derived from the Latin word "*limen*", meaning threshold, is the state of being in-between a previous experience or situation and moving forward towards an emerging situation. It is a state of being betwixt and between the day-to-day realities of life, characterised by ambiguity, in which a dynamic process of experiencing and coping with difficult feelings may occur. This concurs with the work of Boss (2011), who argues that liminality is a transitional factor of the dementia care journey, which is often an unclear and unstable experience, particularly for the dementia caregiver. Within hermeneutic research the interpretation of the experiential perspectives of others taking place

within time, an individual (entity), in this case [I] as researcher, possesses pre-conceptions which can lead to a refinement of [their] understanding in relation to textual and linguistic data elucidated during the interview process (Ajjawi and Higgs, 2007). It is this process which Heidegger (1962) and Gadamer (1960/1989) define as being the *'hermeneutic circle'*. An inter-relationship between the whole and constituent individualised parts of understanding, explored through language.

However, Debesay, Nåden and Slettebø (2008) caution that the hermeneutic circle must not be viewed as a *'circulus vitiosus'* (vicious cycle), from which one cannot escape, but as a place within which knowledge is continuously acquired; a place which Heidegger urges us to "*leap into the circle, primordially and wholly"* (1962: 363). A figurative outline of this circle of understanding by Crotty, (2015) is given in Figure 1. In defining the circle, Ajjawi and Higgs (2007) suggest that the circle is a metaphor for understanding and interpretation, yet from a contextual perspective Smith, Flowers and Larkin, (2009) argue that the concept of the hermeneutic circle speaks to a non-linear style of thinking which functions linguistically on a number of levels within *'the part'* and *'the whole'* as outlined in Table 3. Yet according to Gadamer, (1960, 1997) and McAuley (2006), interpretation within the concept of the hermeneutic circle is more akin to the form of a spiral. A spiralled form of positivity open at the beginning as well as the end, in which new knowledge can be interpreted (Dahlberg, Dahlberg and Nyström, 2008) and thus deterministic assumptions may possibly be avoided (Gadamer, 1960, 1997; McAuley, 2006). In addition, Gadamer regards hermeneutic understanding as being the mediation of the poles of past and present understanding, describing this process as a '*fusion of horizons'* by suggesting:

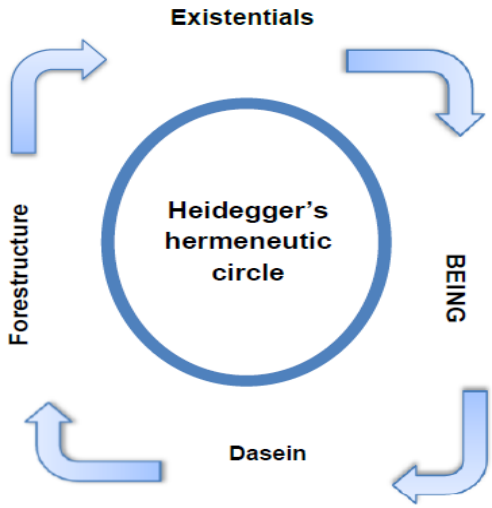
> Understanding is to be thought of less as a subjective act than as participating in an event of tradition, a process of transmission in which past and present are constantly mediated (Gadamer, 1989: 290).

Appertaining to the first part of the hermeneutic circle, Crotty (2015) elaborates on Gadamer's explanation and recognition of tradition (the past), as being the historical effect on consciousness. The second part he reflects as being Gadamer's illustration of the present, the horizon of the interpreter:

> Thus the movement of understanding is constantly from the whole to the part and back to the whole. Our task is to expand the unity of the meaning centrifugally.

> The harmony of all the details with the whole is the criterion of correct understanding. The failure to achieve this harmony means that understanding has failed (ibid: 291).

Figure 1 Hermeneutic Circle of Understanding



(Crotty, 2015:98)

Table 3 The Part and the Whole of the Hermeneutic Circle

The Part	**The Whole**
The single word	The sentence in which the word is embedded
The single extract	The complete text
The particular text	The complete oeuvre (*composition*)
The interview	The research project
The single episode	The complete life

(Smith, Flowers and Larkin, 2009:28)

Gadamer suggests that this is achieved within a dialectic *'fusion*' between the researcher and the participants in the exploration, identification and, as Gadamer suggests, a convergence of the perspectives of understanding. He asserts that:

> To reach an understanding in a dialogue is not merely a matter of asserting one's own point of view, but a change into a communion in which one does not remain what one was (Gadamer, 1960: 379).

The Gadamerian phenomenologist and researcher, Holroyd (2007), simplifies the dialectical concept of the fusion of horizons as being the ability to not only experience, but also to be able to comprehend the fusion of the familiar with the unfamiliar. I interpreted this fusion as the experiential synthesis of my life-world, with the life-world of participants involved with this research study. I achieved this by the design of the research process, the way in which I *'mapped out'* and facilitated the research journey.

3.4 Design and the Mapping Out the Research Journey

3.4.1 Ethical Approval

Ethical approval to undertake this research study and for all accompanying research documentation, outlined below and included in the appendices of this document, was initially obtained from the School of Health, Community, Education Studies Research Ethics Sub Committee, Northumbria University (2009) and subsequently again from the School of Health in Social Science, University of Edinburgh (2012)[9].

3.4.2 Gatekeepers and Participant Recruitment

Branches within the northern region of the Alzheimer's Society in England have previously had a long and successful involvement with dementia related research. Therefore, to engage participation in this research study, I initially made telephone contact with Alzheimer's Society Branch

[9] Following my permanent employment at the University of Edinburgh, I also transferred my PhD course of study to this institution in 2011.

Managers and Family Support Worker colleagues[10], working within six branches throughout the North East of England, to ask for their assistance as *'gatekeepers'* in the recruitment of potential study participants. Three branches were based within urban communities offering support services such as day centre activities for the person with dementia, as well as peer support/luncheon club activities for family caregivers and their cared for family member. The three branches which were based in rural communities only offer peer support and information services for family caregivers.

The following key points relating to the research study were discussed:

- the research topic and why it was being undertaken
- questions which may arise regarding their participation and the recruitment of study participants
- the participants' inclusion/exclusion criteria
- questions which relate to the outcomes of the research.

Involving my Alzheimer's Society colleagues to act as gatekeepers facilitated a convenience sampling strategy in relation to participant recruitment. Researchers such as Bryman (2012), Mackey and Gass (2005) and Robson (2002) argue that there are disadvantages of convenience sampling (also known as haphazard or accidental sampling). They state that this sampling strategy is likely to be biased and should not be taken as being representative of the population. Conversely, Etikan et al. (2016) suggest that the advantage of convenience sampling positions the primary emphasis of knowledge gained as being representative of the population from which the sample is drawn. Furthermore, Dörnyei (2007) and Hultsch et al., (2002) purport that convenience sampling targets population members, enabling the researcher to obtain potential study participants who meet

[10] Prior to the implementation of the NDS (2009) and the introduction of the role of Dementia Adviser, the designated job titles given to my Alzheimer's Society colleagues who undertook a similar role within branches was either Family Support Worker or Carer Support Worker. During the data collection period of this study there was only one branch in the North East of England which employed a Dementia Adviser. This branch was not involved with this research study.

certain practical criteria, such as geographical proximity and accessibility, as well as a willingness to be involved in research.

My approach in applying a convenience sampling strategy was not haphazard or viewed as an easy, hit-or-miss sampling option, but undertaken for both practical and personal reasons. Concurring with the perspective of Dörnyei (2007), I wished to have a geographical spread to include family caregivers residing in urban and rural locations throughout the North East of England. In addition, I was aware that my Family Support Worker colleagues were in a unique position of knowing bereaved family caregivers who had previously accessed services and post-bereavement were still involved with branch activities. Also, they were working with family caregivers currently caring for a relative who were accessing services provided by their branch. More importantly, my co-workers would be conscious of potential study participants, bereaved and current, who would perhaps feel at ease with being interviewed with regard to their individual caregiving role. The involvement of my Alzheimer's Society colleagues would also ensure the availability, if required, of offering further support to participants post-interview.

From a personal perspective I was still, during this period, an employee of the Alzheimer's Society and therefore I considered myself as an *"insider researcher"* (Reed and Procter, 1995; Brannick and Coghlan, 2007; Kacen and Chaitin, 2006; Padgett, 2009). Thus, from the outset of this research journey I was aware of not *"blurring the boundaries"* between my working role and that of academic researcher. Consequently, I was reluctant, for a number of reasons, to contact family caregivers directly myself. Given my duration of employment with the Alzheimer's Society and the former positions I had held, as well as my unusual surname, I was somewhat well known within the Alzheimer's Society northern regional community. Also, to eliminate personal bias, I sought to exclude family caregivers with whom I had a previous or current working relationship. As well as family members with whom I did not have a working relationship, but where I had a previous or current working relationship with their cared-for family member, the person with dementia.

My Alzheimer's Society colleagues working within the six branches who were contacted agreed to take part in this research study and to act as gatekeepers in guiding and introducing me to potential research participants. There was one exception however, an inner city branch offering carer support

services to members of ethnic minority groups which made the decision not to be involved. At the point of contact, colleagues at this particular branch were experiencing staff changes and re-development. In particular, this related to the anticipated expansion of the Alzheimer's Society *One Society*[11] consultation process. Therefore, it was mutually agreed that their involvement would not be realistically feasible. Initial contact was then followed up with a personalised letter to each of my five Alzheimer's Society colleagues, who had agreed to take part in this research study. The contents of which repeated the aim of this study, as well as information relating to their role in the research process (Please see Appendix 2.0).

In contrast to my MSc research study, which explored the experiences of older male spousal caregivers, the inclusion criterion for this research study was open to all family caregivers regardless of relationship; whether they were spousal, children, or other family members. Several additional points as to the inclusion criteria for potential participants were also highlighted. With regard to potential members of participant group one, for example, as having experienced the physical loss of their family member within the last five years. This was to ensure that they were able to reflect on their journey as being a fairly recent experience. Also, unlike the study undertaken by Peacock, Hammond-Collins and Forbes (2014), which involved caregivers who had experienced bereavement within the last twelve months, I stipulated that potential participants involved with this study group had to have experienced the first anniversary of the physical loss of the cared-for-person. I felt that having passed this landmark anniversary event that they would not feel emotionally vulnerable in undertaking the interview. This resonates with bereavement literature which highlights that individuals' experience increased psychological distress during the first year of their bereavement (Cook, 1995; Lattanzi-Licht, Kirschling and Fleming, 1989; Parkes, 1995; Osterweis, Solomon and Green, 1984: Stroebe and Schut, (2001).

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[11] In 2003 the board of trustees of the Alzheimer's Society called for a full consultation review of the society's structure, which led to the development and application of the *One Society* programme. This review programme comprised a series of changes to infrastructure and working practices, envisaged to enable the Alzheimer's Society to provide more services to people living with dementia. In 2010, during the period of my research data collection, there was a further consultation process undertaken with staff and volunteers.

With regard to the exclusion criteria, even though I wished to include potential study participants from ethnic minority groups, I felt that it was necessary to stipulate that potential participants should be confident in speaking English. This was to ensure that, during the course of the interview(s), I was able to interpret the subtle nuances of our exploratory conversations. I also highlighted that potential study participants currently involved with bereavement counselling services could not be involved. The reason for this was that I felt that it could be detrimental to their psychological wellbeing, as well as their ongoing relationship with their counsellor and to the interview process being undertaken with myself.

During the course of my working practice both with the Alzheimer's Society and also with Cruse Bereavement Care I had extensive experience of working with adults and felt that the inclusion of children within this research study was not within my area of expertise. An explanation of inclusion and exclusion research criteria for participant group one (PG1) and participant group two (PG2) is outlined in Tables 4 and 5 respectively. In addition, the documentation sent to my Alzheimer's Society colleagues included an introductory letter (please Appendices 3.1 and 4.1), reference copies of the *Information leaflet* for potential participants (please see Appendices 3.2 and 4.2) and the *Your Journey as a Caregiver leaflet* for potential participants who were bereaved family caregivers (PG1) and current family caregivers (PG2) (please see Appendices 3.3 and 4.3).

Table 4 Participant Inclusion and Exclusion Research Criteria: PG1

Inclusion Criteria	**Exclusion Criteria**
➢ They had previously been a family caregiver for a relative with dementia. ➢ They have been bereaved for more than twelve months and less than five years. ➢ That they were open to discussing their caregiving experience during a single recorded interview. ➢ Were still in contact with their local Alzheimer's Society branch to ensure that they could, if they so wished, access carer support services post-interview.	➢ Where English is not their first language. ➢ Family caregivers or their family member with whom I had previously worked. ➢ Are currently receiving or are actively seeking bereavement counselling. ➢ Less than 18 years of age.

Table 5 Participant Inclusion and Exclusion Research Criteria: PG2

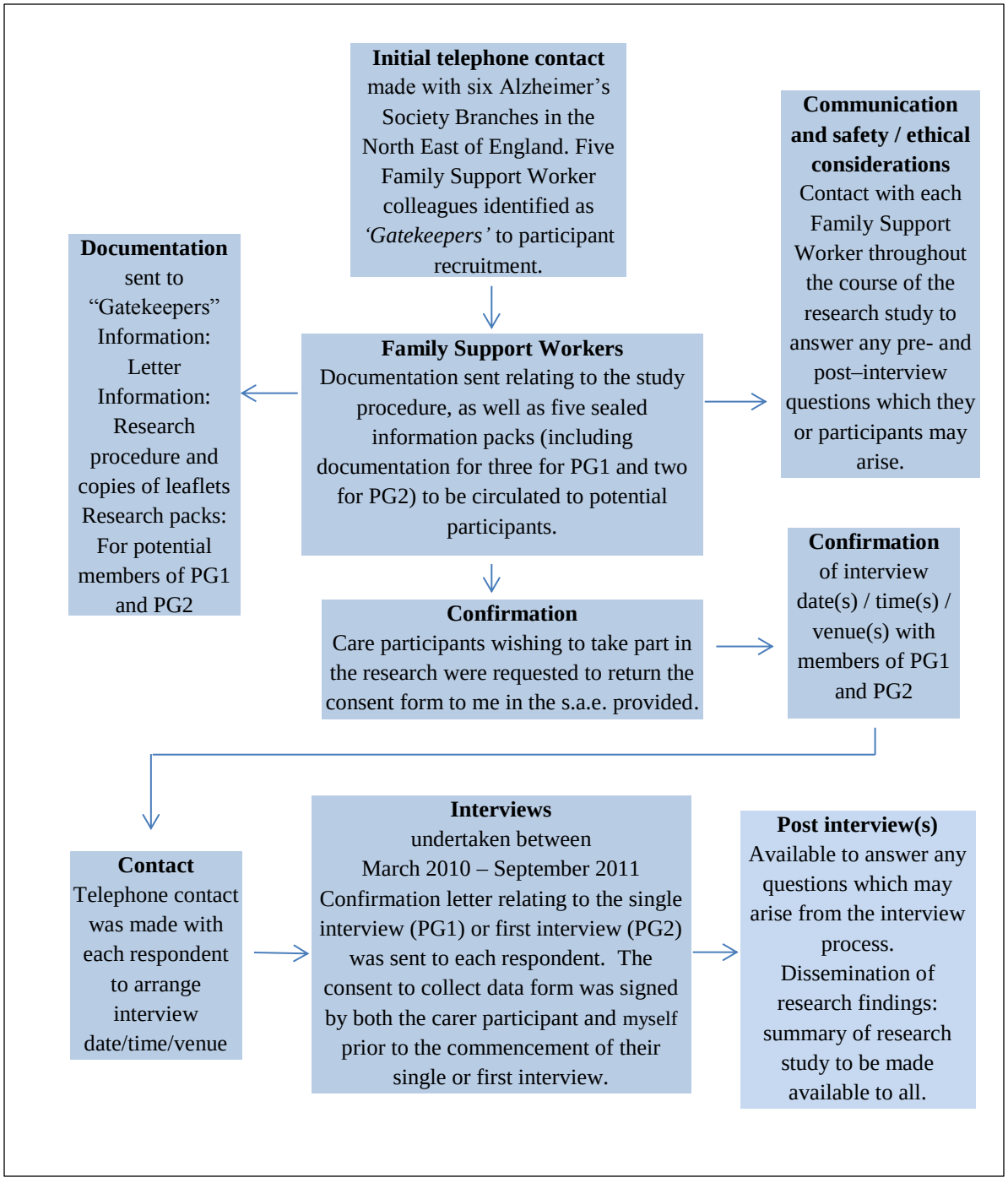
Inclusion Criteria	Exclusion Criteria
➢ Currently caring for a person with advanced dementia who is still residing at home, or is currently living in permanent residential care. That they were open to discussing their caregiving experience during three recorded interviews over an 18 month period. ➢ Were still in contact with their local branch to ensure that they could, if they so wished and if required, access carer support services during or after the completion of the study.	➢ Where English is not their first language. ➢ Family caregivers or their family member with whom I had previously worked. ➢ Who are currently receiving or are actively seeking bereavement counselling. ➢ Less than 18 years of age.

Five sealed packs for individual members of PG1 and PG2 were also included, with a request to my colleagues to circulate these to potential study participants. In order to reduce potential concerns, the complete research study packs for both PG1 and PG2 contained sufficient guidance for potential research participants to make an informed choice regarding consent. As well as the opportunity for them to contact me directly if they wished further clarification before agreeing to take part in the study. The *Your Journey as a Caregiver* leaflet included a declaration of consent to contact form, which the participant was then requested to complete and return to me in an enclosed stamped addressed envelope provided. A confirmation letter relating to the single interview (PG1) or first interview (PG2) was then sent to each respondent (please see Appendices 3.4 and 4.4 respectively). A figurative outline of the participant recruitment process is given in Figure 2.

3.4.3 Safety and Wellbeing on the Research Journey

Even though all of the participants were known to my Alzheimer's Society colleagues, I felt that consideration must also be given to the physical and emotional wellbeing of all involved. As stated in the '*Your Journey as a Caregiver'* leaflet, all participants were given the option of being interviewed at their local Alzheimer's Society Branch, within their own home, or alternatively at Northumbria University.

Figure 2 Participation Recruitment Process



These appointments were then scheduled into my research and work diary. For safety purposes my Alzheimer's Society colleagues working within the branches involved with this study were informed of my timetable[12]. All of the study participants requested that their interview(s) be conducted within their home environment, which I was happy to undertake. However, I was aware that other people, unknown to my Alzheimer's Society colleagues, may also be present when I was visiting the home of the participant. Therefore, in addition, as a safety procedure, I always carried my mobile phone with me and informed the Alzheimer's Society Family Care Worker of each branch of the time of my arrival/departure when making a home visit.

3.4.4 My Inner Compass

As previously highlighted, I was mindful that in undertaking this research I was in fact an insider researcher. I was fully aware that in the collection of my research data that I may have a post-research relationship with many of the potential participants (whether they were colleagues or participants), whilst carrying out the future remit of my Alzheimer's Society role(s).

Therefore, I felt that it was particularly important to highlight the points below to all participants:

- Did not feel coerced or obligated with regard to participating in the research.
- Were reassured that they could withdraw from participating in the research at any time and that such a withdrawal would not influence their status as either an employee or service user of the Alzheimer's Society.
- Were informed and felt comfortable that the research was being carried out in relation to my status as a PhD research student at Northumbria University and not as part of my role as a trainer and project supervisor with the Alzheimer's Society.
- Were given my contact details at the Postgraduate and Research Support Unit at Northumbria University, as well as my personal mobile telephone number.

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[12] A policy of *'point of contact'* between Alzheimer's Society employees and their branch whilst making home visits was introduced by the organisation in 2009.

Stating these points in documentation sent to my Alzheimer's Society colleagues and potential study participants I felt would establish clear boundaries relating to our individual roles and that the expectations of the study would be clearly highlighted.

3.4.5 Theoretical Concepts Applied

In the planning of this research journey I was again drawn back to Steinbeck's quotation and his suggestion relating to "*what to take".* I viewed this as being not only the interview schedule and digital recording equipment, but also my counselling '*skills-based-equipment'*. With regard to the collection of data relating to sensitive health-related topics, Egan (2007) suggests the application of a counselling interview approach as a data collection tool. He advocates the fostering of a therapeutic viewpoint during the interview process in addressing the possibility of reinstating memories which participants may find to be too painful. To ensure that the interview process not only elucidated robust research data, but also that the participants felt that they were in a person-centred relationship and that they were being listened to, I drew on my counselling skills in the empathic restating, reflection and paraphrasing of the experiences offered by each participant.

Counselling and psychotherapy researchers Sutton and Stewart (2008) highlight three essential qualities which are crucial to a person-centred relationship, within the context of counselling therapy, which I felt were also applicable to the interview process of this research study. These are the ability to:

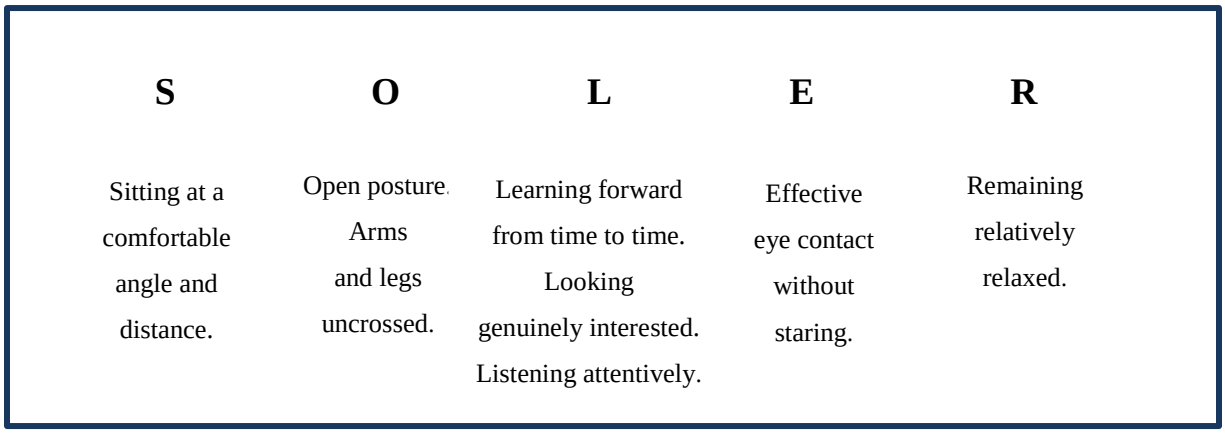
- Demonstrate genuineness or congruence: being '*oneself'* (this I interpreted as *"me being me"* and in doing so applied to the interview process a genuine openness, congruence and an adoption of a *'realness'* attitude during my exploratory conversations with the study participants).
- Unconditional positive regard: accepting and respecting the participants' views of expression (undertaking this without judgement).
- Conveying an empathic understanding: (offering a compassionate approach). (ibid: 27).

With reference to congruence and bereavement, Thorne (1984) states that bereavement workers cannot expect their clients to travel further than they themselves have journeyed. I viewed this with particular regard to the experiential journeys I have previously undertaken, not only with family caregivers during and people experiencing bereavement in my working practice, but also the experience of loss and bereavement in my own life. From a counselling perspective, Rogers (1980) highlights that unconditional positive regard, within the counselling process, requires that the therapist experiences *"a warm acceptance of each aspect of the client's experience as being a part of that client"* (ibid: 234). Applying this to older adults, O'Leary (1996) proposes that because unconditional positive regard is opposed to labelling, it provides a welcome antidote for members of this age group who may be experiencing stereotypical views attributed to them by others. Sutton and Stewart (2008) suggest that empathic understanding requires that the counsellor possesses: the ability to step into the *"client's world"*– as if you are in their shoes and without losing the *"as if quality"* (ibid: 27).

During this research study, I felt that I was not only stepping into the *"lived-world"* of each participant, but also empathically joining them on a reflective journey of their individual caregiving experience. Therefore, drawing on my counselling skills and the notion of *'attending'*, which Sutton and Stewart refer to as *"the act of demonstrating that we are physically and emotionally available to the client"* (2008: 91) is something which I also felt to be a beneficial application during the qualitative interview process with study participants. To illustrate this Egan (2007) offers the acronym SOLER (Figure 3), which he defines as encapsulating the non-verbal skills required to stay attuned with the client; in this case the study participant. Effective non-verbal communication is part of my skill set which I believe I have acquired and enhanced during my many years of working with people who have experienced bereavement, as well as my experience of working with people with dementia (caregivers and the person with dementia themselves), where non-verbal skills are so often required during the course of conversations.

However, from a nursing perspective, Stickley (2011) postulates the model of SURETY which advances Egan's SOLER model, requiring the interviewer to: sit at an angle; sit with uncrossed legs and arms; be appropriately relaxed; maintain eye contact; use appropriate touch to show compassion and to utilise *'your'* own intuition.

Figure 3 SOLER Contact during the Interview Process



(Egan, 2007: 75)

In relation to the latter two components of Stickley's (2011) model of effective non-verbal communication, I perceived that the application of *'touch'* may be misconstrued by participants involved with this research study, especially if participants chose to be interviewed within their own home. I was mindful of personal safety relating to the participants and myself, as well as not overstepping the boundaries of my role as researcher.

Nevertheless, I anticipated that compassion could be addressed in other ways, for example pausing or stopping the interview process if the study participant became emotionally distressed. With regard to the component of SURETY relating to *'your'* own intuition, I felt that this would be addressed in utilising a continuous interpretive approach as to the way in which participants responded both verbally and physically during the interview process.

3.4.6 Participants on this Research Journey

> Sometimes, reaching out and taking someone's hand is the beginning of a journey.
> At other times, it is allowing another to take yours (Nazarian, 2010).[13]

Vera Nazarian's quotation, from her book: *The Perpetual Calendar of Inspiration* is extremely pertinent in reflecting my initial expression of the way in which I anticipated and, more importantly, wished to undertake this research study. I envisaged the participants involved in this research journey as my *'guides'*, welcoming me and inviting me to cross the threshold into their experiential world of dementia caregiving, in order to facilitate a dialogically shared perspective of their individual landscapes of care. As previously discussed, the involvement of the two participant groups of family caregivers of people with dementia was not undertaken as a comparative study, but to engender an expansive view of the retrospective experiences of bereaved caregivers (members of PG1) and the past, present and anticipated future experiences of current caregivers (members of PG2).

3.4.7 Membership of Participant Group One (PG1)

The single 60-75 minute interview conducted with the individual members of PG1, comprising twenty former/bereaved family caregivers, enabled the formation of a generic and panoramic vista in relation to my initial aim of exploring [with them] their experiences of their individual dementia caregiving landscapes. This enabled the extrapolation of preliminary knowledge of the membership of PG1 with regard to participants' gender, the relationship to the cared-for-person and their connection to their local Alzheimer's Society branch (please see Table 6). Within this table I have also highlighted the reason for their involvement in this research study.

To ensure clarity of understanding within this dialogical exploration during the course of the interview process for both participant groups, I was mindful of using my counselling skills, by

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[13] The quotation is the entry for July 5th from *The Perpetual Calendar* of Inspiration by Vera Nazarian (2010) and is not denoted by a page number.

continuously reflecting back to each participant my understanding of their individual experience. This involved the reflective repetition of individual words relating to their emotions expressed by participants, such as *'happiness', 'sadness', 'fear' and 'anger'.*

Table 6 Membership of Participant Group One (PG1)

Membership of PG1	**Gender / relationship to the cared-for-person**	**Reason for involvement**
Twenty bereaved participants all of whom were of white British origin and were interviewed only once. Participants who were still involved with their local branch of the Alzheimer's Society: either as members of peer support for other family carers / groups, or within a funding / awareness raising capacity	➢ Eight spousal male carers. Aged between 75 - 84 years. ➢ Nine spousal female carers. Aged between 65 - 83 years. ➢ One father and daughter dyad. Aged 84 years and 59 years respectively.	To retrospectively explore the experience of family caregivers throughout their entire dementia caregiving journey and post-bereavement.

In addition, the reflection of groups of words or the paraphrasing of complete sentences was also undertaken during the course of each interview.

For example:

- Participant: *"I am just cared out."*
- Me: *"You feel tired of caring."*
- Participant: *"No, I am tired, but I still care, I still <u>want</u> to care for her."*

The paraphrasing of words and sentences not only enabled the participant to make a reasoned sense of what they were trying to convey to me, but also ensured that participants felt that they were being *'heard'*. In addition, it facilitated clarity of my understanding and extraction of the true meaning of their lived-experience. I felt that restating, reflection and paraphrasing their experiences during the course of the interview was sufficient in achieving an expansive and retrospective view of the dementia caregiving landscape experienced by bereaved family caregivers, and that it was

unnecessary to return transcribed data to this particular group. The fundamental reason for this format of data collection was that I was conscious that the members of this study group were one-year or more post-bereavement in relation to the loss of their family member, the cared-for-person, and were possibly beginning to, or had already relocated themselves within a post-bereaved environment.

3.4.8 Membership of Participant Group Two (PG2)

Concurrent to the single interviews with PG1 members, three separate 60-75 minute interviews were also scheduled and undertaken during six monthly intervals across the course of an eighteen month period (from March 2010 – September 2011), with the ten members of PG2. Please see Table 7 which outlines my preliminary extraction of information relating to the membership of this group, with regard to participants' gender, the relationship to the cared-for-person and their connection to their local Alzheimer's Society branch.

As with members of PG1, during the first interview with participant members of PG2, I again utilised my counselling skills to continuously reflect back to each participant my understanding as to their experiential descriptions. This was to clarify the representation of understanding and subsequent *'co-ordinates of interpretation'* of their recollected caregiving experience, prior to further exploration of their caregiving journey.

The second and third interviews undertaken with members of PG2 commenced with a retrospective review of transcribed data collated during our previous interview. The third interview with members of PG2 involved the same format as for the one-off interview with members of PG1 in the para-phrasing of words and expressions.

Table 7 Membership of Participant Group Two (PG2)

Membership of PG2	**Gender / relationship to the cared-for-person**	**Reason for involvement**
Ten participants all of white British origin, currently caring for a family member living with an advanced experience of dementia. Four participants were providing care to their family member within their own home, with the support of local authority care staff and staff members of their local Alzheimer's Society branch. The remaining six members co-participated with care staff in the provision of the caregiving requirements for their family member within a permanent residential care setting within their locality. Scheduled to be interviewed on three separate occasions (at six-monthly intervals) over an eighteen month period. All participants were also currently involved with local carer support groups and /or an Alzheimer's Society Family Support Worker.	➢ Four spousal male caregivers. Aged between 74 - 85 years. ➢ Three spousal female caregivers. Aged between 64 - 83 years. ➢ A father and daughter dyad. Aged 85 years and 58 years respectively who were living separately within their own homes, but caring for their wife/mother who was living in permanent residential care. **NOTE:** One spousal female caregiver aged 65 years (who was interviewed only once, due to the imminent and anticipated loss of her husband who had been diagnosed with pneumonia).	To allow for a more in-depth exploration of their entire journey and towards the end of life of the person, their family member, for whom they were currently caring.

3.4.9 Synopses of Participant Group One (PG1)

The twenty members of PG1 were allocated an individual interview code number ranging from 1-20. For example, *'Jane'*, who is listed as the first member of PG1, is denoted as: Jane: (PG1/1). Following the same format of enumeration, transcribed verbatim quotations, including notations of non-verbal expressions are discussed in chapter five of this document. A brief synopsis of each participant which outlines background information relating to themselves, their cared-for-family member, dementia diagnosis (if known / given) and additional support received is outlined in Tables 8(a-e).

Table 8(a) Synopses of Participant Group One (PG1): Bereaved Participants

Participant's name / gender / age / name of cared-for family member and relationship / location	**PG1 + / interview code number: (1-5)**	**Background information: Dementia diagnosis (if specified) and additional support by other family members and participants' involvement with their local branch of the Alzheimer's Society (AS)**
Jane **Female: 65 yrs.** Husband: Norman [Rural location]	**1**	Married for 41 years, Jane and Norman had two grown-up children both of whom lived locally and who supported Jane in caring for Norman at home. Norman had received a diagnosis of early on-set Alzheimer's Disease in 1998. He had died five years prior to the interview. Jane continues to attend her local (AS) family carers support group.
Alan **Male: 85 yrs.** Wife: Ethel [Urban location]	**2**	The couple had been married for over 60 years. In the final ten years of Ethel's life Alan had cared for her at home. An initial diagnosis of dementia had been difficult to obtain. Ethel had died two years prior to our interview. Alan continues to be involved with his local AS branch in a fundraising capacity.
John **Male: 79 yrs.** Wife: May [Rural location]	**3**	John and May were married for 58 years. They did not have children, but lots of support from their extended family (nephews and nieces), neighbours and from the (AS) Family Support Worker. In the final two years of May's life they had daily support from local authority care staff. John often attends support groups and fundraising events at his local AS branch.
Margaret **Female: 84 yrs.** Husband: Joe [Rural location]	**4**	Married for 63 years prior to Joe's diagnosis of dementia in 1999. Margaret described their relationship as being *"childhood sweethearts"*. The couple had accessed support services, but permanent residential care was not an option that the family had wished to consider. Their two children, both of whom live locally, were extremely supportive in caring for Joe. Margaret is still in regular contact with the (AS) branch.
Susan **Female: 82 yrs.** Husband: Ronald **[**Rural location]	**5**	Ronald and Susan had celebrated their 60th wedding anniversary one year before Ronald died of cancer in 2005. Susan and Ronald were supported by their three children. Susan still attends the AS support groups for family carers.

Table 8(b) Synopses of Participant Group One (PG1): Bereaved Participants

Participant's name / gender / age / name of cared-for family member and relationship / location	**PG1 + / interview code number: (6-9)**	**Background information: Dementia diagnosis (if specified) and additional support by other family members and participants' involvement with their local branch of the Alzheimer's Society (AS)**
Dave **Male: Aged not specified** Wife: Moira [Rural location]	**6**	Married for 42 years to Moira, Dave had cared for her at home, until her death four years prior to being interviewed. Dave had received lots of support from family members who lived locally, as well as from AS branch staff. He continues to be involved with the local AS branch, particularly with peer support meetings involving male caregivers.
Lucy **Female: Age not specified** Husband: Ralph [Rural location]	**7**	Lucy and her husband Ralph were married for over 45 years. Their four children live within the locality and were extremely supportive to their parents after Ralph's diagnosis of Alzheimer's related dementia in 2000. Sheila had been proactive in seeking support from her local AS branch, not only for herself, but also for Ralph. The couple had also accessed respite care, until Ralph entered the same care home on a permanent basis in 2005. Ralph died three years prior to Lucy being interviewed.
Sheila **Female: 74** Husband: Gary [Rural location]	**8**	Married to Gary for 40 years, Sheila has two children, one daughter who lives nearby and their son, who lives in the south east of England. Sheila had been aware of the deterioration of Gary's memory for a number of years. Gary was diagnosed with possible vascular related dementia in 2000. He died whilst living in permanent residential care in 2006, three years prior to Sheila being interviewed.
Molly **Female: 76** Husband: Ben [Rural location]	**9**	Ben, Molly's husband was diagnosed with vascular dementia in 2000. He and Molly had been married for 42 years. Molly has a large and extended family, three daughters and two sons. Together they assisted Molly in caring for Ben whilst he was still living at home. Ben entered permanent residential care in 2000 and died in 2007.

Table 8(c) Synopses of Participant Group One (PG1): Bereaved Participants

Participant's name / gender / age / name of cared-for family member and relationship / location	**PG1 + / interview code: (10-14)**	**Background information: Dementia diagnosis (if specified) and additional support by other family members and participants' involvement with their local branch of the Alzheimer's Society (AS)**
Patricia **Female: 72 yrs**. Husband: Nigel [Urban location]	**10**	Patricia had been married to Nigel for over 45 years. They did not have children. The couple had accessed services such as those provided by their local AS branch, as well as respite services offered by the local authority. In 2006, towards the end of his life, Nigel entered permanent residential care. Patricia still attends a peer support group for family carers facilitated by the local AS branch.
Joyce **Female: 61 yrs.** Mother: Alice (Father: Bob PG1/19 - group one dyad) [Rural location]	**11**	Part of PG1 father and daughter dyad, Joyce had previously supported her father (Bob, PG1/19) in caring for her mother, Alice. Prior to a diagnosis of dementia, Alice had experienced other issues of ill health. Joyce and her partner live next door to her parents' home. Whilst caring for her mother Joyce had received additional support for both her parents and herself, provided by the local AS branch. Alice died in hospital in 2008, two years prior to Joyce being interviewed.
Brian **Female: 81 yrs.** Wife: Nell [Urban location]	**12**	The couple had been married for 55 years. They had no children, but lots of support from nephews and nieces. After Nell received a diagnosis of Alzheimer's related dementia in 2003, Brian had been able to care for Nell at home with the ongoing assistance from their neighbours, the AS Family Support Worker and local authority care workers. Brian is still an active fundraising member of his local AS branch.
George **Male: 81 yrs.** Wife: Mabel [Urban location]	**13**	Married for over 56 years. An initial diagnosis of dementia had been given after visiting their GP with regard to another health issue being experienced by Mabel. George had cared independently for Mabel for a number of years until he made contact with the AS. Subsequently, Mabel had accessed the AS day centre and local authority respite care until her death in 2004. George keeps in regular contact with his local AS branch and other family caregivers.
Linda **Female: 69 yrs**. Husband: Henry [Urban location]	**14**	Linda and Henry had been married for 35 years. The family had emigrated from the UK in the 1970s, but in the early 1990s the family had to return to England due to Henry's ill health. Henry received a diagnosis of early onset vascular dementia in 1995. Linda had made contact and had accessed a carer support group at her local AS branch. She continues to be involved with the branch in a fundraising capacity.

Table 8(d) Synopses of Participant Group One (PG1): Bereaved Participants

Participant's name / gender / age / name of cared-for family member and relationship / location	**PG1 + / interview code: (15-18)**	**Background information: Dementia diagnosis (if specified) and additional support by other family members and participants' involvement with their local branch of the Alzheimer's Society (AS)**
Brenda **Female: 68 yrs.** Husband: Don [Urban location]	**15**	In 1999, Don and Brenda had been married for 42 years. It was in this year that Don was diagnosed with Lewy Body related dementia and Brenda was guided by her GP to access carer supportive services offered by the AS. Brenda had cared for Don at home with support from family members, until Don entered permanent residential care in 2003. He died in 2006, four years prior to Brenda being interviewed.
Maggie **Female: Age not specified** Husband: Si [Urban location	**16**	Maggie described that she and Si had been *"happily married"* for 41 years and had two daughters, both of whom lived locally. In 1996, Maggie had become increasing aware of Si's cognitive impairment and contacted the GP. She had independently cared for Si at home. In the final years of Si's life Maggie sought assistance from the AS regarding information and guidance. Subsequently, she became involved with peer support activities provided by the AS. Si's death in 2005, although anticipated, had still been an overwhelming shock for Maggie. She still maintains her connection with the AS branch and other family caregivers.
Burt **Male: 69 yrs.** Wife: May [Rural location]	**17**	Burt was married to May for over 50 years. He expressed that his relationship with May had been that of a deeply inter-connected couple. They had no children, but one niece who was extremely supportive. May had experienced several falls outside of their home. Burt was initially unaware of what may be the cause of these falls, until May was diagnosed with dementia after a referral to the hospital by their GP. With the assistance of his niece, Burt contacted the local AS branch. He continued to care for May at home until her death in 2007.
Jessie **Female: 69 yrs**. Husband: Barry [Rural location]	**18**	Jessie and Barry had been married for over 45 years. Jessie felt that perhaps her dementia caregiving journey had begun 17 years prior to Barry's death in 2006. She had independently cared for Barry for 10 years. During the latter half of her caregiving journey Jessie was supported by their four children, as well as the AS Family Support Worker. Jessie remains in contact with the AS branch by attending carers' events such as coffee mornings, etc., but has become increasing worried regarding the decline of her own memory and what this may mean in the future.

Table 8(e) Synopses of Participant Group One (PG1): Bereaved Participants

Participant's name / gender / age / name of cared-for family member and relationship / location	**PG1 + / interview code: (19-20)**	**Background information: Dementia diagnosis (if specified) and additional support by other family members and participants' involvement with their local branch of the Alzheimer's Society (AS)**
Bob **Male: 87 yrs.** Wife: Alice (Daughter: Joyce PG1/11 - group one dyad) [Rural location]	**19**	Bob expressed that he and Alice had experienced a wonderful life together and that they had been *"blessed"* with two children. Alice's diagnosis of dementia had initially been problematic, given her additional health issues. Part of the PG1 father and daughter dyad, Bob had been supported by his daughter Joyce (PG1/11), who had encouraged them to attend support groups facilitated by their local branch of the AS. After Alice's death, both he and Joyce have remained in contact with the AS branch and other family caregivers.
Roy **Male: Age not specified** Wife: Evelyn [Urban location]	**20**	Two years before Evelyn's death in 2006, Roy and Evelyn celebrated their golden wedding anniversary. Roy expressed that it was their daughter, who lives locally, who had taken Evelyn to the GP in 1999. This was in response to increasing concerns regarding her mother's ill health. In 2002, a diagnosis of vascular dementia was given by the consultant psycho-geriatrician. On their behalf, their daughter had contacted the local AS branch and both Roy and Evelyn attended the monthly luncheon club for over two years, before Evelyn's death.

3.4.10 Synopses of Participant Group Two (PG2)

With regard to the interview transcriptions relating to PG2 members, the same numeric format was also applied, with the allocation of an interview code number ranging from 1-10, as outlined in Tables 9(a-c). As with members of PG1, a brief synopsis of each participant is also given in these tables, which highlights background information relating to the participant, the cared-for-family member, dementia diagnosis (if known/given) and additional support received. In conjunction with interviews undertaken with PG1 members, a total of three interviews with PG2 participants were undertaken at six monthly intervals over the eighteen month data collection period. Interviews one, two and three with participant members of this group are identifiable by the letters /a, /b, or /c respectively. For example, quotations and discussion relating to *'Avril'*, undertaken during our first interview are denoted as Avril: (PG2/1/a). Subsequent quotations and discussion relating to *'Avril'*

transcribed from the second interview are denoted as Avril: (PG2/1/b) and from the third interview as Avril: (PG2/1/c).

Table 9(a) Synopses of Participant Group Two (PG2): Participants currently caring for a family member with an advanced experience of dementia, living either at home or within a permanent residential care environment

Participant's name / gender / age / name of cared-for family member and relationship / location	**PG2 + / interview code number: (1-3 + / a, b, or c)**	**Background information: Dementia diagnosis (if specified) and additional support by other family members and participants' involvement with their local branch of the Alzheimer's Society (AS)**
Avril Female: 73 yrs. Husband: Tom (living in permanent residential care) [Rural location]	**1**	Avril and Tom have been married for 48 years and had lived together in their current family home for 30 years prior to Tom entering permanent residential care in 2003. Finding an appropriate residential care home within the locality was extremely difficult. Avril and Tom have two sons, both of whom live within the area and have supported their parents since Tom's dementia diagnosis in 1999. Avril was allocated a social worker after Tom's diagnosis. She regularly attends a carers group and finds the support offered to be extremely beneficial.
Rachael **Female: 64** Husband: Ted (living in permanent residential care) [Urban location] **Final Interview**	**2** **PG2/2c**	Rachael and Ted had been married for 39 years prior to Ted being sectioned under the Mental Health Act in 2003. Rachael had been unaware of any issues relating to Ted's cognitive ill health prior to this event. She contacted the AS branch to ask for information and support and was allocated a Family Support Worker after Ted was diagnosed as having dementia after being sectioned under the Mental Health Act. **NOTE:** Our final interview took place six months after the second interview. Sadly during this period Ted had died, but Rachael adamantly wished to be interviewed, stating that she wanted to *"share her experience"* in the hope that it would *"help other family carers"*.
Eric Male: 81 yrs. Wife: Penny (living at home) [Rural location]	**3**	Penny, Eric's wife of 52 years is living at home and being cared for by Eric and their daughter. Penny received a diagnosis of Lewy Body related dementia in 2002 and both she and Eric were referred to their local AS branch for additional support services. The family was allocated an AS Family Support Worker and find this helpful in addressing the changing requirements of caring for Penny at home. Eric does not attend any peer support groups for family caregivers.

Table 9(b) Synopses of Participant Group Two (PG2): Participants currently caring for a family member with an advanced experience of dementia, living either at home or within a permanent residential care environment

Participant's name / gender / age / name of cared-for family member and relationship / location	**PG2 + / interview code number: (4-7 + / a, b, or c)**	**Background information: Relationship to the person with dementia, dementia diagnosis (if specified) and additional support by other family members and by the local branch of the Alzheimer's Society (AS)**
Harry **Male: Age not specified** Wife: Kathy (living in permanent residential care) (Daughter: Marie –PG2/5) [Rural location]	**4**	Harry stated that Kathy, his wife of 61 years, had "*memory problems"* and was now living in permanent residential care. He and Kathy have one daughter, Marie (**PG2/5**). Both Harry and Marie live in remote rural locations, several miles apart. The family have ongoing monthly contact with the AS Family Support Worker, which they find helpful. During the course of the three interviews Harry reflected his emotions and responses via "*Lindi",* the family's toy poodle.
Marie Female: 60 yrs. Mother: Kathy (living in permanent residential care) (Father: Harry PG2/4) [Rural location]	**5**	Marie expressed her deep sadness and regret that her mother had been placed in permanent residential care in 2005, four years prior to our first interview. Kathy had been diagnosed with dementia in 2001, but Marie highlighted that clinicians had suggested that Kathy may have a mixed diagnosis of vascular related dementia (and possibly alcohol related dementia). Marie supports her father Harry (PG2/4) in caring for Kathy. They both keep in regular contact with the AS Family Support Worker. Marie finds this extremely helpful.
April Female: 77 Husband: Billy (living at home) [Urban location]	**6**	April and Billy have been married for 53 years and have a large and supportive family, all of whom live within the locality. With the exception of their son Stuart who died seven years ago. Decisions regarding Billy's care are always undertaken collectively by the family, including Billy's opinion. April contacted the local AS branch soon after Billy received his dementia diagnosis in 2001. Subsequently, Billy attended the weekly AS day club, until his health began to deteriorate.
June **Female: 81 yrs.** Husband: Sid (living in permanent residential care) [Urban location]	**7**	June and Sid have been married for 22 years and together they have no children. However, June has three children from her previous marriage, who live locally and try to offer practical and emotional support. Sid was diagnosed with vascular related dementia in 2004, but his health deteriorated rapidly within a year. Sid entered permanent care in 2007, but June remains unhappy about this decision in not being able to continue to care for Sid at home.

Table 9(c) Synopses of Participant Group Two (PG2): Participants currently caring for a family member with an advanced experience of dementia, living either at home or in permanent residential care

Participant's name / gender / age / name of cared-for family member and relationship / location	**PG2 + / interview code number: (8-10 + / a, b, or c)**	**Background information: Relationship to the person with dementia, dementia diagnosis and additional support by other family members and by the local branch of the Alzheimer's Society (AS)**
Alex **Male: 79 yrs.** Wife: Sheila (living at home) [Urban location]	**8**	Alex has been caring for his wife Sheila at home for over 10 years. Sheila was diagnosed with Lewy Body related dementia in 1998. Emotionally Alex described his experiences of not only caring for Sheila but also, during the past 15 years, that he had cared for his mother and his sister-in-law. Alex and Sheila are supported by the Family Support Worker of their local AS branch, who has been visiting them twice a month for over four years. In addition, local authority domiciliary care workers assist Sheila twice per day. Alex feels incredibly lonely and isolated.
Alma Female: Age not specified Husband: Tom (living in permanent residential care) [Urban location] **First interview**	**9** **PG2/9/a**	Married for 44 years, Tom and Alma have two daughters who live within the locality. Both daughters were described by Alma as being extremely supportive. Tom was diagnosed with Alzheimer's Disease in 2002 and Alma, at the suggestion of their GP, made contact with the AS branch. They were allocated a Family Support worker who has been extremely supportive. Tom entered permanent residential care in 2009. **NOTE:** The first interview with Alma had been scheduled, but when I arrived at Alma's home she told me that on the day prior to our appointment she had been informed by the nursing staff of the permanent residential care home in which Tom was living, that Tom was very close to his *"final days"*. Nevertheless, Alma adamantly requested that we proceed with the interview, stating that by speaking she wanted to "*help other families"* in the same situation.
Bill Male: 80 yrs. Wife: Mary (living at home) [Rural location]	**10**	Mary and Bill met and were married when they were both in their early twenties. They have one son who lives abroad, but who keeps in regular contact with his parents. Mary was diagnosed with dementia in 1997 and for the past 8 years has experienced decreasing mobility and speech difficulties. Bill has cared for Mary at home with support from local authority care workers. Bill has support from family friends and is able to attend the local AS carers group which he helped to initiate four years ago.

3.4.11 Interview Venue and Additional Data

Prior to the commencement of the interview process of this research study, I was aware of the possible asymmetry of power between myself as researcher and the participants taking part in this study. Kvale (1996) argues that as the researcher is setting the agenda of the interview, asking the questions and subsequently analysing the data, then they are perhaps perceived as having the power. Conversely, Thapar-Bjorkert and Henry (2004) suggest that in answering the questions, it is the participants who determine the outcome of the research. I wanted to ensure from the very beginning that participants would feel comfortable in co-directing the semi-structured interview process. Therefore, each participant was given the option of being interviewed within their own home, at their local Alzheimer's Society branch office or at Northumbria University. All thirty participants involved with this study chose to be interviewed within their own homes. I felt this was not only a conducive environment in which participants would perhaps feel more secure in exploring their individual and personal journeys, but I also anticipated that this setting would add to the depth of my understanding and subsequent interpretation of their experience of *'being*', within their *"lived-world"* of care-giving.

To assist in the analysis and conceptualisation of collated data brief field notes were written immediately after each interview. As suggested by Burgess (1991), Czarniawska-Joerges (2007) and Wolfinger (2002), these notes were typed up within twenty four hours of each scheduled interview. Bryman (2012) purports that the inclusion of field notes, particularly in qualitative research, *"may be useful for acting as a springboard for theoretical elaboration of the data"* (ibid: 447). Whilst Ravitch and Carl (2016) highlight that field notes should contain descriptive information, enabling the researcher to understand the culture, social environment or phenomenon being studied. The content of my field notes outlined information relating to each participant, such as gender; age (if given); dementia diagnosis of their family member (if known / given); relationship status to their cared-for family member; additional support; emotional expression of the participant; repetitive themes; residential location and the mood-as-atmosphere of the interview environment. Collectively, these notes outlined my initial perception of the overall ambience of the interview undertaken and the initial identification of emergent themes.

However, Doucet (2008) asserts that the research communities to which we belong are permeated by not only theoretical, epsitemological and ontological assumptions, but also by personal conceptions we may hold, which have subtle and/or explicit outcomes. Therefore, before and after each interview brief entries were also written in my reflective diary, to offer a personal perspective relating to my emotions, such as how I was feeling before, during and after each interview. As with my field notes, my diary entries were typed up within twenty four hours of each interview and allocated to the named/coded study participant. Researchers such as Mauthner and Doucet (2003) posit that reflexivity is recognised within social science and can be utilised as an interpretive resource, but argue that the practicalities and methods in the research process are rarely addressed.

Nevertheless, D'Cruz, Gillingham and Melendez (2007) highlight that reflexivity within academic research is often debated as being interchangable to, or to be differentiated from the concepts of reflectivity and critical reflection; yet academic literature appears to replicate a consensus in relation to intrepretation. Denzin and Lincoln (2000) purport that keeping a reflexive diary can be a cathartic process. Whilst Roller and Lavrakas (2015) and Stronach, Garratt and Pearce (2007) suggest that the process of reflexivity engenders a continual internal dialogue and critical self-evaluation of the researcher's positionality. In doing so it provides a recorded first-hand account which may highlight interviewer bias and possible preconceptions that may have negatively influenced the findings of the study.

However, in her article: *Negotiating the swamp: the opportunity and challenge of reflexivity in research practice*, Finlay (2002) cautions that engaging in the process of reflexivitiy can also be ambiguous and problematic, comparable to journeying through a complicated landscape of perilous paths of uncertainty. Neverthless, Linda Finlay advises that reflexivity can be understood from various perspectives vis-à-vis the aim(s) of the exercise at stake and the theoretical or methodological style applied. The challenge of reflexivity she adds is:

> to negotiate a path through this complicated landscape – one that exposes the traveller to interesting discoveries while ensuring a route out the other side (ibid: 212).

Discussions relating to my thoughts during the research process, together with excerpts from my reflective diary are given in section 3.6 of this document.

3.4.12 The Interview: *"Please Tell Me About Your Journey*"

All of the forty eight interviews undertaken with the thirty participants involved with this research study were undertaken during an eighteen month period. Each interview for both participant groups was undertaken within an agreed and pre-scheduled 60 – 75 minute time slot and was digitally recorded. However, I chose not to take notes during the interview process, but to proceed with an exploratory conversation with the participants, in which they had my undivided attention. Also, throughout the course of all of the interviews I ensured that I was attentive to the facial, body and vocal responses of each interview participant. For example, the radiant facial expressions of love when reflecting on happier and *'sunnier'* times, contrasted with the *'dark clouds'* of animated anger in response to the recollection of challenging events relating to their caregiving role. I was also continuously mindful of my own responses. The way in which, perhaps, I would be perceived within this interview relationship and how I would, could and should respond, both physically and verbally, to what were often the recollections of emotional and extremely personal journeys offered by each participant.

The single interview with members of PG1 and the first interview with members of PG2 commenced with a verbal *"thank you"* to the participant for welcoming me into their home and for agreeing to take part in the research study. I then outlined issues in relation to informed consent, confidentiality, ownership and accountability as suggested by Lofland et al. (2006). Each participant was assured that their names and the names of their family member(s) would be anonymised in the writing up of my research. In addition, that our digitally recorded discussion could and would be paused or completely abandoned at their request, particularly if they became distressed or did not wish to continue being involved with the study. Once this was clarified and the participants felt happy to proceed, I requested that they sign and date the declaration of consent to collect data form (please see Appendices 3.5 and 4.5). This document was then countersigned, dated and retained by me. During the interview process several participant members of PG1 and PG2 did request that we take a pause in our discussion. This was to talk about extremely personal

aspects of their caregiving experience which they wanted to talk about, but did not wish to be recorded as part of the research study.

In terms of data collection I chose a semi-structured interview format, as Morse and Field (1996) suggest that this format, compared to structured interviews, provides greater depth and richness to data. Bryman (2012) also argues that qualitative interviews undertaken using this format enables study participants the freedom to respond to questions and probes in the reiteration of their individual experiences, without being tethered to specific answers. All participants were initially asked the *'grand tour'* question *"Please tell me about your journey whilst caring for <name of the person with dementia>"*; which initiated the one-off interview with members of PG1 and the initial members of PG2. Participants were then encouraged through prompt and reflective questions (if and when required), to explore their experiences in relation to aspects of their personal caregiving journey (please see Appendix 5.0 for interview question/prompts).

In the final question at the end of the interview with members of PG1 and after the third and final interview with members of PG2, participants were also asked to look back at their '*landscape of care'*. In doing so they were invited to consider aspects of guidance they would offer to other family caregivers, or from a reflective perspective, if they had not expressed this during the course of the interview(s), what they felt they had wished they had undertaken differently whilst carrying out their caregiving role.

Following the completion of the first and second interviews with PG2 members, an agreed date and time was confirmed for subsequent interviews two and three respectively. A follow up telephone call was made to each PG2 participant two weeks prior to interviews two (b) and three (c) being undertaken, to ensure that participants were still available and willing to be involved in the research study. After the single interview with PG1 participants and on completion of the third interview and final interview with nine members of PG2, the participants were each given a personalised *'thank you'* card.

However, one participant member of PG2 was interviewed only once. This was due to the fact that at the point of scheduling our first interview and the interview taking place, she had been informed by care staff, of the residential home in which her husband was living, that he had developed

pneumonia and given the fragility of his health that his death was imminent. Nevertheless, this participant stated that she wished to continue with the first interview, saying that she wanted to "*help other families"*. We agreed that subsequent interviews would not be undertaken. The day after this interview had taken place I sent a *'thank you'* card to this participant, which also expressed that my thoughts were with her and her family.

I was also mindful that during the course of the interview process with all of the participants I would be asking them, during the exploration of their individual journeys, to talk about extremely personal and emotive issues relating to their caregiving role. Although this study did not involve any invasive intervention and was therefore unlikely to cause any harm to participants, I fully recognised that the discursive and reflective nature of the interview process could potentially be emotively distressing. To ensure that participants were able to discuss any issues which had arisen during the course of the interview process, I factored a further forty five minute post-interview period into my interview time slots to ensure that each participant was not left in a state of emotional distress. This period was always taken up with conversations over a cup of tea; sometimes even two cups of tea. I again highlighted that further support could be offered by my Alzheimer's Society Family Support Worker colleagues if required. None of the participants expressed that they felt that they would require further support in relation to the interview process, but stated that they hoped that their individual experiences would be beneficial to other family caregivers.

For security purposes, with regard to myself and the study participants, I had also arranged to contact my five Alzheimer's Society Family Support Worker colleagues, to confirm that the single or initial interview with participants had taken place. I also reminded my colleagues that I was available to clarify any questions which may arise after the interview process from study participants who were involved with their particular branch. In addition, all of the participants involved with this study consented to be contacted by me for any follow-up questions and for purposes of participant validation if required. Subsequently, follow up questions initiated by study participants, Family Support Workers or myself were not required. My Alzheimer's Society colleagues and all of the participants involved with PG1 and PG2 were informed that a summary of the research findings would be made available on completion of the research study.

3.5 A Step-by-Step Approach to Data Coding and Analysis

> The scientific observer is part and parcel of the setting, context and culture he or she is trying to understand and represent (Altheide and Johnson, 1994: 486)

Creswell (2007) argues that qualitative research is often viewed as employing inductive reasoning which enables the researcher to begin with specific observations, before moving towards the detection of recurrent themes and patterns emerging from the collected data. However, Cresswell (2009) further highlights that the various aspects of qualitative research possibly involve the researcher not only having to spend an extensive amount of time in the field, but that they are often working with the collation of complex data. Highlighting that conclusions change and continuously evolve as more data is collected. In undertaking an inductive approach I was aware that I had to continually contemplate my own fore-structures of understanding (as previously discussed in this chapter), and orientation towards the experiences of participants during the exploration of their individual caregiving journeys. This was in order to facilitate my complete attunement with the perceptions of participants in relation to the co-creation of the thematic data presented. I was also aware of the argument highlighted by Cohen, Kahn and Steeves (2000) who argue that "*findings of a hermeneutic phenomenological study can be judged only in the context of the intellectual discourse it joins and creates"* (ibid: 92).

This process of reflexivity continued throughout the duration of this study, as previously highlighted with the inclusion of field notes and notations within my reflective diary. Smith, Flowers and Larkin, (2009) suggest that the inclusion of additional data with the analysis process further enhances transparency and honesty in the subsequent analysis of collected data. Nevertheless, Cohen, Kahn and Steeves (2000) purport that the analysis of research data begins during the interview process itself, in the practice of active listening and interpretation of the narrative experiences offered by participants. Progressing this further, Backman and Kyngäs (1999) suggest that data analysis is akin to a discussion between the actual data, research notes and the researcher. This discussion occurs within a process whereby the research data is broken down, conceptualised, re-conceptualised and subsequently codified into thematic data.

The process of analysing the data for this research study was undertaken in four inter-related steps:

- Step One: Locating the participants within the research landscape
- Step Two: The adaption and application of the theoretical framework of anticipatory grief
- Step Three: Exploring the caregiving landscape and the conceptualisation of schemas of self
- Step Four: Re-conceptualising the fluctuating schematic representations of self

3.5.1 Locating the Participants within the Research Landscape

Robson comments that "*qualitative data can easily become overwhelming, even in small projects"* (2002: 476). Therefore, the digital recording of each of the forty eight interviews was transcribed and a preliminary reading was undertaken within twenty four hours of the interview taking place. This process, as well as my initial thoughts, field notes and reflective diary entries completed after each interview, offered a broad-brush view of the caregiving terrain of each individual participant. In undertaking this activity the transcriptions highlighted a number of generic aspects in relation to the interview process itself. For example, both male and female members of PG1 and PG2 were extremely forthcoming in sharing their experiences. They frequently anticipated the next step of the interview in their recollections of their caring journey, which often made my semi-structured interview schedule of questions obsolete. Following their lead I asked further probing and reflexive questions, as well as paraphrasing their responses. This course of action was to clarify that my initial understanding of the content of our exploratory conversation was correct.

Researchers such as Finch and Groves (1983), discussing the ethics and politics of research interviewing, suggest a gender differentiation between males and females. They state that where a female researcher is interviewing female participants, then this is "*a situation with special characteristics conducive to the flow of information"* (ibid: 74). Nevertheless, in transcribing the interviews I found that male participants were equally, if not more forthcoming in the exploration and sharing of their experiences. At the end of the interview process, during the single interview with members of PG1 and the third and final interview with participants involved with PG2, all participants expressed that it had given them the opportunity to talk about themselves and their

caregiving experiences. Some stated that although it had at times been extremely emotive, it was also self-affirming and even therapeutic.

In addition, during this initial preparatory stage each interview transcript relating to the individual participant was given a code number. Also, the names of the participants, the cared-for-person, other family members, clinicians and other care workers referred to throughout the quotations (as offered in chapter four of this document) were anonymised. The geographical names relating to diagnostic and support services, provided by the health service, local authority workers, as well as branches of the Alzheimer's Society which had previously or were currently accessed by the participants and their family members, were removed. Before becoming fully immersed in the research data, during the course of undertaking a preparatory reading of interview transcriptions I certainly began to grasp an initial *'feel'* of the cartography and experiences of each participant within their landscape of care.

Commencing a preliminary reading and the preparatory codification of all interview transcripts also reminded me of my *'introduction'* to each participant's family member, the person with dementia. This was undertaken with the viewing of photographs, spontaneously offered by participants either at the beginning, or during the course of their individual interviews. Customarily these were wedding or family group images in sepia, black and white or colour print, which represented happier and *'sunnier'* events experienced during the course of their life together. In addition, prior to commencing four of the initial interviews with PG2 members Eric, April, Alex and Bill, I had the pleasure of being introduced to their spousal partners who were living with an advanced-stage-experience of dementia and who were being cared for within the family home. These pictorial and physical introductions enabled the beginning and development of humanising and illuminating the caring journeys of each participant.

3.5.2 The Adaptation and Application of the Theoretical Framework of Anticipatory Grief

In October 2011, after the eighteen month period of data collection had been completed, I undertook a second reading of each interview transcript. The forty eight transcriptions were printed out in hardcopy format. I began with the twenty transcripts relating to the interviews undertaken with members of PG1. With regard to the study participants of PG2, each of the three interview

transcriptions (labelled as: /a. /b. and /c) were read sequentially for each individual. As suggested by Saldaña (2009), I meticulously read through the transcriptions line-by-line, not only to reacquaint myself with the content of the interviews, but also to enable me to begin to reflect on the contents of the data. Also, as per the recommendation of Charmaz (2006), I made preliminary notations in the left hand margins of the transcripts to outline my initial interpretation of emerging thematic codes. These codes were units of meaning, including individual words and phrases which described the phenomena of the lived-experiences of caregiving. My notations supplemented by my field notes and associated entries written in my reflective diary enabled me to explore and examine the relationship between emergent themes and to compare these themes to pre-existing literature and theory.

Reading all of the transcripts together was a daunting process and I soon became fully aware of the argument presented by Cresswell (2007) that qualitative research involves the collation of complex data. Therefore, the process of analysis and storage of data became a paramount consideration. Initially, I had contemplated using NVivo 8^{TM} computer software for the storage of the data, as McLafferty and Farley (2006) suggest that the application of software packages such as NVivo and NUD*IST during the analytical process facilitates research data to be mapped, linked and visualised, enabling theory development.

Nevertheless, as with most journeys, even research journeys, routes often change. Even though I have since been involved with research that has utilised NVivo software, I felt that employing this *"technological filing cabinet"*[14] for this particular research study would be an alien feature in my research landscape. I compared it to the application of a mechanical process to achieve fitness, for example, using a cross-trainer machine in a gym, as opposed to physically walking within an external environment. From a practical perspective, Noble and Smith (2014) argue that one of the disadvantages in the application of on-screen software packages is that it may impede the visualisation and conceptualisation of data by the researcher. Taking this perspective into consideration I envisaged that utilising NVivo software would not enable me to become fully

[14] An illustrative term used by a friend and colleague who is an NVivo specialist and trainer.

immersed within the data. Metaphorically speaking I wanted to empathically *'touch'* and to emotionally *'feel'* the data and therefore I concur with academic writer and psychologist Paul Gilbert who suggests that:

> It is our emotions that give colour to our lives; they texture all that we do. With emotions, things matter: without them, they may not. Our capacity to feel links us to things we value (2010: 139).

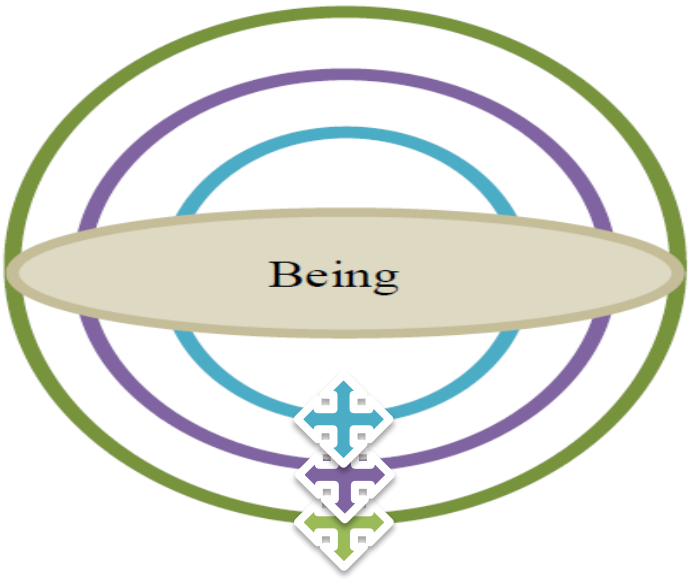
Therefore, the initial analysis of data was mapped, linked and visualised manually in a tabled format. Subsequently, this proved to be a long process generating copious data notes which were appropriately categorised, coded and stored relating to each study participant. The thematic coding and editing process of interview transcriptions (step one), and then the second reading and preliminary notation of the collective data (step two), highlighted that the exploration of the individual landscapes of care experienced by participants were similarly presented within a chronologically referenced timeframe. Given that the study information provided to participants pre-interview and the content of the consent form and interview schedule referred to the dementia caregiving journey, the emergence of cartographical themes was anticipated.

It is at this point of the analysis process that the theoretical framework comprising the psychological, interpersonal and socio-cultural aspects of anticipatory grief, as outlined by Fulton and Fulton (1971), Fulton and Gottesman (1980), was applied across the entire dementia caregiving landscape experienced by each participant. The adaptation of this framework during a third reading of the interview transcriptions assisted in formulating the data and superordinate themes into a stratified tri-dimensional representation of participants' experiences of their caregiving journey.

Enabling the interpretation relating to participants' experiences of the psychological day-to-day aspects of caregiving, represented in this study by the foundational sub-themes within an expansive *'topographical landscape'*. Sub-themes within the smaller second stratum, the *'communicative landscape'*, highlight the emotive responses of participants relating to specific inter-personal experiences with their cared-for relative, family members and care workers. The third stratum reflects the *'orientation of self and wellbeing within the landscape'*; the emergent sub-themes are

associated with strategies and routines currently or previously undertaken by some of the interview participants during the course of their caring role.

Figure 4 Locating the Participants within the Stratified Dementia Caregiving Landscape



The adapted application across the entire caregiving journey of the theoretical framework of anticipatory grief and loss originally presented by Fulton and Fulton (1971), Fulton and Gottesman (1980). The adapted framework is reinterpreted and presented as a tri-dimensional landscape relating to caregivers' experiences of change, loss and bereavement during their caregiving journey.

The topographical landscape: the foundational and expansive stratum representing the interpretations of participants' experiences of the psychological day-to-day aspects of caregiving

The communicative landscape: the second stratum associated with emotive responses of participants' relating to specific inter-personal experiences with their cared-for relative, family members and care workers.

The orientation of self and wellbeing within the landscape: the third stratum relating to strategies and routines currently or previously undertaken by some of the interview participants during the latter and post-bereavement periods of their caregiving journey.

I also found it helpful to formulate my interpretation and conceptualisation of thematic data within a diagrammatical format. Corbin, Strauss and Strauss (2014) suggest that diagrams and figures function as visual devices which document and stimulate analytical thought. Researchers such as Miles and Huberman (1994) argue that diagrams do not need to be elaborate, but can be utilised:

> to map likely relationships, to divide the variables that are conceptually or functionally distinct (ibid: 22).

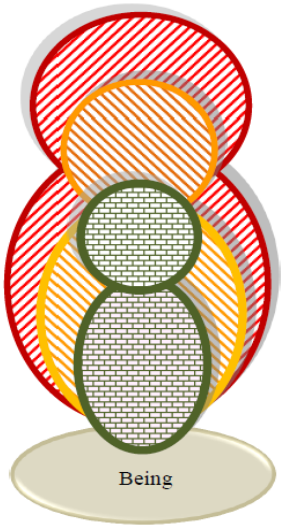
I offer a diagrammatical representation of my interpretation of locating the participants within the stratified dementia caregiving landscape in Figure 4.

3.5.3 The Caregiving Landscape and the Conceptualisation of the Schemas of Self

Following on from the process undertaken in steps one and two of data analysis, a fourth reading of each transcript was collectively carried out, whilst at the same time listening to the associated digital recording of each interview. This process was to capture a discovery-orientated structure of the exemplars of thematic meaning, whilst attending to both the verbal and non-verbal elements of the interview recording. For example, the subtle pauses, intonation and emphasis of emotional expressions presented by study participants. In this process I fully entered the hermeneutic circle in seeking to engage with the phenomenon of dementia caregiving. As researchers such as Crotty (2012); Smith, Flowers and Larkin. (2009) assert, this is an iterative process of development, requiring continuous movement back and forth, to encompass the whole and constituent parts of the research data to generate emergent interpretation.

This cycle of the analysis of the data highlighted thematic patterns which were identified and extrapolated to help pinpoint the pertinent leitmotifs of the caregiving experienced across the entire caring journey. Again, as with step two, marginal notes were added and refined. However, intersecting with this layered landscape the analysis of data also reveals a key aspect of caregiving relating to participants' physical and emotional responses in undertaking their caregiving role. The emergence of a conceptual framework involving three interconnected, schemas of self and being experienced by participants: *me-self, relationship-self and caregiving-self.* A diagrammatical interpretation of the schemas of self and being is depicted in Figure 5.

Figure 5 The Three Schemas of Self and Being



Caregiving-self: associated with the acquisition and undertaking of their role of familial caregiver.

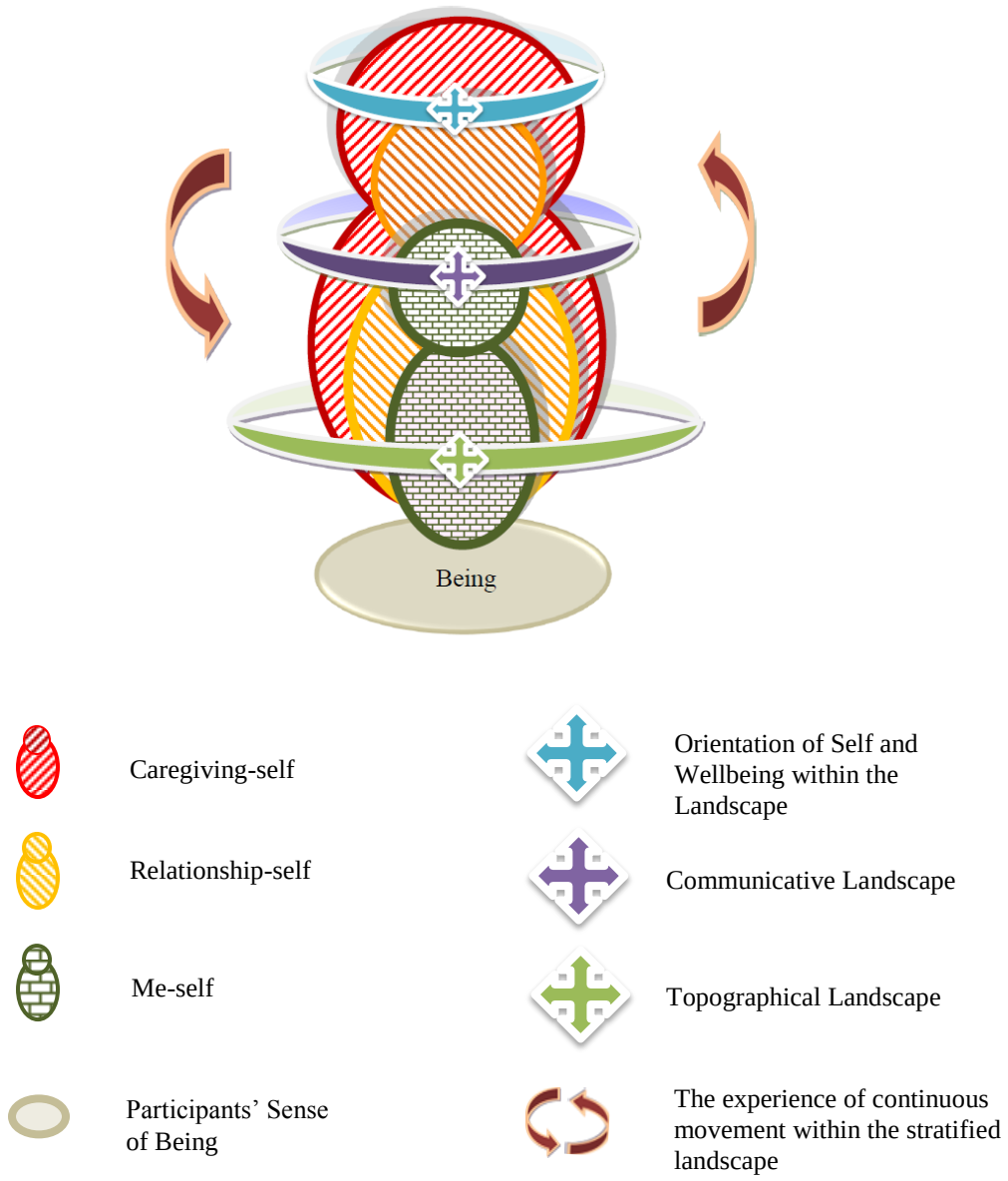
Relationship-self: illustrates participants' physical and psychological experiences and bonded connection between themselves and the cared-for spousal partner or parent, as well as other family members and care workers.

Me-self: participants' perception of their core self and envisaged sense of self.

Participants' Sense of Being

Although unlike the foundational *me-self*, the latter two senses of self, the *relationship*-self and *caregiving-self*, were afforded interpretative precedence by caregivers during the course of our exploratory conversations.

Figure 6 The Fluctuating Perceptions of Self and Being within the Landscape



3.5.4 Re-Conceptualising the Fluctuating Schematic Representation of Self and Being

Further analysis and interpretation of participants' schemas of self and being within their individual caregiving journeys highlighted an emotive oscillating time-shift process of stopping, acknowledging their present, reflecting upon their past and looking forward to their future horizons. In their presentation of their experiences, participants *'spoke'* from each of their three schemes of self in relation to their physical and emotional responses in undertaking their caregiving role.

However, their sense of self appeared to conceptually fluctuate in representing, either positively or negatively, participants' experiential and emotional perspectives of *'being'* in the dementia care landscape. This perpetual movement in relation to their overall schemas of *'self'* and *'being'* added to the complexity of the cartography of caregiving experienced by the participants. A figurative depiction of the fluctuating perceptions of the schematic representation of self and being within the stratified dementia care landscape is offered in Figure 6. This illustrative format relates to the participants' overall psychological wellbeing and their internalised belief regarding not only anticipated, but also their perceived management of outcomes within their previous, current and future landscape of care.

Nevertheless, my methodological approach in undertaking the analysis of data, my *'being'*, my *'presence'* within this research landscape should also be acknowledged. Therefore, to ensure credibility of the analysis and interpretation of data the next part of this chapter relates to my location within the landscape during the course of this research study.

3.6 Locating Myself within the Research Landscape

> More often than you realise it, the world is shaped by two things – stories told and the memories they leave behind (Nazarian, 2010).[15]

Again returning to the writing of Vera Nazarian, I feel that she offers a succinct definition as to the way in which our *'lived-worlds'*, our experiential views of reality are formed. Poignant and emotive events, whether they are happy or sad, become our memories. Our personal narratives are shaped into reminiscences of previous journeys undertaken both physically and cognitively, which we may choose to internalise or to share with others. Researchers such as Koch and Harrington (1998) assert that a deeper understanding of research is required in the politics of *'location'* of the researcher and the subsequent influences on research data. Berger (2015) suggests that reflexivity is a demonstration of self-supervision applied by the researcher, which offers a: *"transparent report of decisions and their rationale"* (ibid: 222). It is for this reason that the following sections outline my reflexive view of my location and orientation within the landscape of dementia care, in relation to my own experiences of grief, loss and bereavement whilst undertaking this research study. My initial diary entry begins by outlining my earliest memory of change, grief, loss and bereavement.

3.6.1 Early Memories of Change, Grief, Loss and Bereavement

Looking back, as a young child I think that the true reality of death often eluded me. Although this is possibly not an accurate statement of fact because, on reflection, it appeared that the actions of others, namely my mother and other family members ensured that, rightly or wrongly, I avoided experiencing such emotional life events. Such *'happenings'* were often hidden away from me. Grandparents and older family friends were physically one day a part of my life, and the next day they were not. Over time distant relatives and family friends became more distant and less talked about, as if they hadn't really existed, or even more mysteriously defined as being *"before my*

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[15] The quotation is the entry for August 24th from *The Perpetual Calendar of Inspiration* by Vera Nazarian (2010) and is not denoted by a page number.

time". From a young age I would often assimilate this information as being my lack of any identifiable relationship and attachment with these people. I concluded that somehow it must be my fault that I was not a part of their familial legacy. On reflection, I believe that at the time the exposure to such ambiguous remarks perhaps had a profound and converse effect with regard to my experiential development. Nevertheless, in later life I would often invest in and cherish the reciprocal bonds of affection of my future relationships. An antithetical course of action which I believe was a mechanism through which I was then able to positively come to terms with the loss of those whom I have loved (and still love) during the course of my life. A course of action which echoes, as Bowlby (1980) suggests in his theory of attachment, that the bonds of human interaction often tie individuals together from their birth to death and emotionally even beyond.

During my childhood the concept of death was certainly baffling to me. Periodically, I noticed that elders within our local community would *'disappear*' from the neighbourhood. This invariably would be followed by the perplexing and ritualistic actions undertaken by their relatives of closing the curtains and shrouding the person's home in darkness; whilst neighbours within the community reminisced in whispered tones. For a gregariously *'chatty'* child, with at this point in time no siblings, I recall that such events were also often acknowledged by the enforcement of my silence. For several days following a person's disappearance from the community, I was not permitted to play outside due to my family's traditionally held belief that - *"all good children should be seen and not heard"* - especially on such occasions as this. Subsequently, my acts of playing and talking would be confined to my room, where I felt temporarily incarcerated being only able to talk to my Matryoshka dolls.[16] This period of imprisonment, although appearing to me to be an eternity, in reality amounted to one or two days and was offered vicariously by my family as a sign of muted respect to the departed: their departure to *"where?"* I would often ask, although of course I was

[16] Matryoshka or Babushka dolls are the names given to Russian nesting dolls. Often considered as decorated pieces of wooden and painted Russian handicraft, they are perhaps better known as being a toy for children. Made up of a series of several dolls of varying sizes, they can be individually placed one inside the other to interlock and formulate part of one large whole. However, my perceived reality as a child was that each of *"my dolls"*, whether I viewed them as being male or female, had their own individual self-narrative. During the course of our conversational play, I found that separately these dolls always had *"something"* to share with me.

seldom told. Nevertheless, I do remember that in the days and months that followed I did, on some level, experience the loss of these people from my life.

Such as the elderly neighbour with the cross-over pinny, braided hair, crinkly skin and lovely toothless smile, who would often mistakenly call me Maureen, Sylvia, Joan or Johanna, the names of my mum, aunts and grandmother. Nevertheless, on these occasions I never corrected her, remaining quiet, as I felt that again this was another occasion where I should perhaps be *"seen, but not heard"*. Maybe because I naïvely perceived myself as being a guest in her reality and for that reason, or another, it seemed much kinder to remain silent. Unless of course it was in response to a direct question or gesture, which would then necessitate a short, but polite reply. I remember that prior to her *"departure"*, which as a child was so unanticipated by me, she would wait for me each day after school. Standing at the end of her garden path she would press a brown paper bag into my hand in which she had, invariably, placed a bounty of goodies - an over-ripe banana, a wizened orange, a squashed toffee and sometimes, as a special treat, a bright shiny penny. After she had *"gone"*, above all else I missed her smile. Based or not on factual reality, these are *'my'* memories. Yet looking back over the terrain of my early childhood I now realise that serious illness, death and funerals were confined to and an integral part of the scenery of the lived-experience of grown-ups. For me, the true reality of these events was not a part of the day-to-day tapestry of my life at that time.

3.6.2 The Start of My Understanding of Change, Grief, Loss and Bereavement

In contrast to my early childhood, by 1995 I had experienced a dramatic personal loss. This was the death of my first husband, Mark, who had taken his own life. As next of kin, having been together for seventeen years and spousal partners for over twelve of those years, I was called upon to identify his body. Apart from photographic and cinematic images, Mark was the first dead person I had ever seen *"up close and in person"*. I remember that the final image of Mark was that of a man who bore no resemblance to the person who I had known and loved.

During the course of my work with the Alzheimer's Society, I would often hear caregivers speak about their family member, the person living with dementia, in the same way. The fact that the cared-for-person, whether they were their husband, wife, mother, father, aunt, uncle or friend,

although unlike Mark, were physically present, but did not appear to be *"who they once were"*. They had somehow become cognitively displaced and, at times, physically unrecognisable. Over the years I acknowledged and accepted that I had *'lost'* Mark, he was physically gone forever. Yet the day-to-day experiences of ambiguity in relation to the cognitive and physical losses experienced by family caregivers during the course of the caregiving journeys had a profound effect on me.

In 2004, with the encouragement of the new branch manager and with the agreement of financial support by the Alzheimer's Society branch committee members, I commenced a part-time online MSc in Dementia at the University of Stirling. Four years on from that my MSc dissertation was submitted in 2008. After graduation I was asked to undertake the role of course tutor on the MSc programme and was involved with the facilitation of the End of Life module. Although my experience of study had been hard work, it was nonetheless extremely enjoyable and had whetted my appetite for further study. During this period I was still working for the Alzheimer's Society and periodically undertaking voluntary work for Cruse Bereavement Care, whilst at the same time offering day-to-day support to my parents. Nevertheless, I decided to apply for a full-time PhD studentship at Northumbria University. Successful in my application, I thus began my PhD research journey in 2008, anticipating that even though this research journey would be hard work, it would hopefully be an enjoyable and rewarding experience.

3.6.3 The Unanticipated Part of My Journey: Experiential Events 2008 - 2010

> When you are guided to this pathway, feel the "*rebound*" of reality that allows you to pick yourself up and come to standing again[17] (Douglas-Klotz, 2005: 172).

As we go through life most of us, at some time or another, encounter periods of uneven terrain within the landscape of our life journey. Looking back we may remember some years as being filled with happy and joyous memories, whilst other years are tainted with extremely sad events.

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[17] This quotation is entitled: Al-Qayyum, meaning *"rebounding"* and is taken from the book *The Sufi Book of Life: 99 Pathways of the Heart for the Modern Dervish*. It is a book of meditation exercises, which I have referred to over many years in assisting me to negotiate my experiences of change, loss and bereavement during the course of my adult life.

Unfortunately, 2008 was a mixture of both; commencing my PhD and then later in the year the sudden death of my step-brother, Geordie. Having been in remission from renal cancer for two years, and much to the concern of other family members, he had taken the opportunity to travel to the Far East. Geordie died of an acute myocardial infarction whilst swimming in the sea off Phuket beach in Thailand. Nevertheless, I was comforted by the fact that his life came to an end in a place that he loved. On reflection and perhaps a clichéd assumption on my part, I think that it is what *"he would have wanted"*. During the course of this research study many of the spousal members of PG1 echoed the same feelings when speaking about the final *"loss"* of their husband, wife or mother.

For the next two years my personal life and research study experience progressed without incident. I undertook various activities. Seeking and being granted ethical approval for my research, an initial and second review of literature, contacting my Alzheimer's Society colleagues and recruiting study participants, as well as data collection and transcription and attending monthly supervision meetings with my supervisors. Speaking with a professor from the field of dementia studies during this period, I proffered my assumption that my thesis would be submitted within four years. Her response was *"Jo, don't bank on it, life sometimes impinges on our research"*. In retrospect I now realise how right she was in saying this to me.

However, in 2009 and much to my surprise I even won first prize for my research poster (please see Appendix 6.0) at the first Northumbria University research poster event for postgraduate students. I also presented my poster at a regional event for postgraduate students across the North East of England.[18] All in all, I felt that my research journey was pretty much *'on track'*.

[18] Unfortunately, my poster did not receive the same response as it had done at the Northumbria University event. One of the event officials took a fleeting look at my poster and declared that he was not going to review it as *"it was far too sad a topic"*. Later in the day, one of the other event officials approached me to ask who he should contact regarding his concerns relating to a member of his family, who he believed may have dementia. I reflected that enabling this person to find further support was far better than winning any prize.

3.6.4 When Research Parallels Reality: Experiential Events 2010 - 2012

In March 2010, I began the process of data collection. For the next six months I undertook all of the single interviews with members of PG1, as well as the first of three interviews with members of PG2. As I had envisaged, participants acknowledged a clear delineation between my Alzheimer's Society employee and researcher roles. This I felt was attributed to a combination of the recruitment information documentation initially provided by myself, and further clarification offered by my Alzheimer's Society colleagues. Also the pre-interview explanation of the purpose of the research study during the pre-interview discussion and the signing of the declaration to consent to collect data form by both the participant and myself, assisted in augmenting and defining my position. However, there were occasions during the pre-interview when members of PG1 and PG2 engaged in Alzheimer's Society *'chit-chat'*, such as: *"did I know this person?"* or *"that person?"* I interpreted this as a way for participants and myself to establish a rapport, which hopefully would enable them to feel at ease and ensuring that they felt that they were an equal partner in the co-directing of our exploratory conversation.

The content and ambience of each interview with each of the thirty study participants was different, but nonetheless individually memorable for a variety of reasons. Particularly regarding the environment of the participants' homes, their age, gender and relationship to their cared-for family member. During the course of the first few months of data collection several entries in my reflexive diary related to enduring sadness. For example, my diary entry describing an interview undertaken with Alan (PG1/2) highlighted that: *"*two *years on from the loss of his wife [Ethel], Alan is surrounded by her possessions. His living room is full of bolts of material, balls of wool, as well as several knitting and sewing machines. I certainly felt Ethel's remaining presence within their home".* My final notation written immediately after the interview with Alan stated that: *"this was an extremely emotional interview"*. Also after this interview, which was the last undertaken that day, I returned to my car and had driven home in tears. Subsequently, this prompted me to introduce a strategy of parking my car out of sight of the participants' homes, to enable me to compose myself before and after each interview.

Other interviews, especially with spousal caregivers of both groups, were emotively simlar to the interview undertaken with Alan. Only one interview, the first of three interviews with Rachael (PG2/2/a), was defined by an overwhelming expression of anger. I document it here as an example of how I reflected on my interview skills as being challenged. It began on Rachael's doorstep, when she said: *"Hello … are you Jo? Well I am telling you now I am <u>really</u> angry!"* Rachel's expressions of anger continued throughout the entire interview, during which she spoke about how, in the beginning, she had been totally unaware of her husband [Ted] *"having any problems with his memory whatsoever"*. She continued to say that Ted had been sectioned under the Mental Health Act in 2008, but that he was now living in permanent residential care. She continued to speak about the difficultes that both she and Ted had previously experienced and were currently continuing to experience.

Throughout the interview Rachael became visably restless and verbally animated. Several times I asked if she would like me to pause or stop the interview all together, but her response was always the same: *"No 'pet!', people <u>need</u> to know what goes on"*. At the end of the interview, as with other members of PG2, I ask Rachael if she would like to continue being involved in the study and if so, could we arrange a date and time for the second interview. I noted Rachael's response in my diary which was: *"I didn't think that you would want to come back – I have given you a hard time … I am sorry"*. The second interview was scheduled to take place on 30th November of that year (2010). Following on from this, the interview entries in my diary notated reflexive thoughts related to my *'inner compass'* as I asked myself numerous questions such as:*"why am I doing this research?"; "why am I asking participants to explore their emotive caregiving experiences?"* and *"what do I actually hope to achieve?"* I frequently had to remind myself of the scarity of knowledge and the contribution I was hoping to make relating to family caregivers' experiences of change, loss, grief and bereavement in relation to the entire dementia caregiving journey.

The contents of other interviews with members of both PG1 and PG2 were a mixture of emotional expression. Susan (PG1/5), for example, spoke about aspects of behaviour displayed by her husband Joe whilst caring for him at home. She visably shrank into her chair as she reflected on the behavioural changes displayed by her husband, which at times both she and her daugther had found to be extremely challenging. Within the seventy minute interview Susan moved from being slightly

tearful to fits of laughter, and then back to being tearful. The interview with Susan ended in a chat over a cup of tea, during which she told me that: *"I am alright you know, it has been good to talk…thank you"*.

However, one of the most challenging aspects I experienced and reflected on during the data collection period were my diary entries relating to the meeting and interviewing of the two adult caregiving-daughters, Joyce (PG1/11) and Marie (PG2/5). Who, together with their respective fathers Bob (PG1/19) and Harry (PG2/4), were part of the two caregiving dyads involved with this research study. As with all participants, I was mindful during the interview process (and also throughout the analysis of data) of applying, as Sutton and Stewart (2008) suggest, unconditional positive regard in accepting and respecting without judgement the views of expression presented by each participant. I realised that I had to *'unpack'* and *'separate out'* the true *'essence'* of the lived-experience of caregiving expressed by both women vis-à-vis to those of their fathers. I wrote in my reflective diary that this process would necessitate an *"intensified awareness in my viewing and interpretation of the experiences of all four participants from an individually based perspective"*.

Notations in my diary during this period also emphasised the similarities between Joyce, Marie and myself. We are women born in the 1950s, geographically living within rural environments within the North East of England and currently we all reside in close proximity to our parents. Now, as adult children, we are individually undertaking reciprocal roles of caregiving. Roles which were once provided to us by our respective parents. Notes relating to the single interview with Joyce highlighted this in her perception of self as always having to be *"the good girl, the caring child"*. Marie further elaborated this aspect of self during our first interview by saying that in being an only child she felt an awareness of her sense of self in being *"conditioned to care from a very young age"*.

The perceptions of the schemas of self offered by these women truly reasonated with me. My diary entry for both of these interviews ended with the same statement: *"metaphorically, this interview was far too close to home".* I soon realised, even at this initial stage, that during the analysis process I would need to extremely attentive with regard to disentangling my experiential

perceptions from those expressed by Joyce and Marie, to ensure that their true *"lived-experience*" of dementia care was presented.

The data collection and initial transcription of each interview continued as scheduled during the spring and summer of 2010. I felt that I was still *'on track'* in being able to submit my thesis, until I experienced my second family bereavement; the death of my step-father (Vasil Alexjuk), on 31st October. On that beautiful autumnal day he was sweeping up leaves in his garden to make compost and playing with his dog Ben, when he experienced an acute myocardial infarction. Throughout his life, the man I regarded as being *"my dad"* had always been a demonstrative character. He constantly wished to be placed at the centre of everyone's attention and was notoriously regarded amongst family, friends and our family doctor as someone who thoroughly enjoyed the minor ailments of ill-health. If you had a cold, then Vasil had a cold as well, but of course he was *"suffering"* more and this always had to be acknowledged.

This is in stark contrast to the fact that in the last ten years of his life Vasil appeared to experience mild cognitive impairment; displaying obsessive and challenging behaviour, in particular in relation to money, food and politics. He would engage me in protracted and repetitive conversations about not being able to remember recent events, but more often about episodes in his life that he did not wish to remember. Specifically, his experiences of WW11 and fleeing Russian occupied Ukraine. In addition, he was also experiencing night terrors, invariably associated with *"the Russians are coming"*.

I had begun to notice cognitive changes in Vasil as far back as 1999 as, during our wedding ceremony, Rob and I noticed that Vasil appeared to be extremely confused. In 2003 our family doctor did acknowledge that he thought Vasil, having previously experienced several transient ischemic attacks, and subsequently may be living with vascular related dementia. However, this was not confirmed by the consultant psycho-geriatrician to whom Vasil was later referred, as she suggested that given that his first language wasn't English, she was *"unable to make a conclusive diagnosis"*. After Vasil's funeral, I took a two week break from my research. Even though I had experienced a bereavement I did not make any immediate entries in my diary until my return to data collection at the end of November 2010.

My first interview, after my father's death, was the second interview with Rachael. My diary entry prior to this interview stated my acknowlegement of being: *"reticent with regard to interviewing Rachael again"*. This was not because I had interpreted her expressions of anger during our first meeting as being personally directed at me, but that she was simply *"voicing the overwhelming challenges"* she had experienced and felt that she was continuing to experience in caring for her husband. However, I was mindful of feeling *"rather vulnerable"* and that perhaps the ambience of this interview may replicate the last. I was wrong. Rachael opened her door to me and without pausing for breath said:

> *"Hello pet, I saw your father's death in the paper and the girls at the branch [Alzheimer's Society] said that they thought that it was your dad because he had the same name as yours. Did he have dementia? How did he die? And would you like a piece of cake with your tea?"*

In my response to Rachael I was attentive of not over-stepping the boundaries of research practice. In conducting the interviews with all of the participants I had always been conscious of the preservation of boundaries within the interview relationship, particularly in drawing on my counselling training relating to the non-disclosure of personal information. However, from a psychotheraputic perspective, Zur (2009) posits that within counselling, disclosure which goes beyond the sharing of required information, such as name, contact details, relationship policy, etc., becomes self-disclosure. Nevertheless, Zur (2009) further asserts that the sharing of information may be unavoidable, but often engenders transparency within the relationship. This concurs with a study undertaken by Dickson-Swift (2007) involving the interviewing of thirty qualitative researchers working within the field of health studies. Dickson-Swift asserts that self-disclosure in research, particularly associated with sensitive topics, was often perceived by their study participants as requiring:

> A need to create some sort of *'level playing field'*, acknowledging that self-disclosure could enhance rapport, show respect for the participants and validate the participants' stories (ibid: 332).

Rachael had asked me several direct questions regarding the loss of my father and I felt that on this occasion that self-disclosure was appropriate, and so I briefly answered her questions. Yet during

our pre-interview cup of tea she empathically asked me a further and more probing question about *"my"* dementia caregiving role, *"who did I talk to about being a carer?"*

I offer this example, not as a self-indulgent illustration, but as one which I found to be thought provoking for two reasons. Firstly, Rachael's question relating to my role as a caregiver highlighted an aspect of my life which, up until that point, I had failed to recognise. Reflecting on Rachael's question, I found myself at a point of liminality, a location, as Blandin and Pepin (2015) argue in their dementia-related research, as '*being*' between a previously perceived location, whilst at the same time moving forward towards an emerging situation. With the asking of one question by another person my perception of self, of who I was, changed immediately. Post-interview I reflected that: *"not only was I a researcher and worker within the field of dementia care, but that I had also undertaken my own dementia caregiving journey"*. The second point relating to Rachael's question is associated with my observation that the relationship between Rachael and myself had also altered. In responding to her questions in an honest and transparent manner, she appeared to be more at ease with me during this interview and our third and final interview.

The final interview with Rachael was scheduled to take place in April 2011. During a telephone conversation to highlight the date and time of this interview with my Alzheimer's Society colleague who was supporting Rachael, I was informed that Ted, Rachael's husband, had died. I contacted Rachael by telephone to offer my condolences and she adamantly stated that she wanted to continue being involved with the study. She echoed what she had said at the very beginning of our first interview, that *"people need to know what goes on",* but then added *" ... even at the end".* Given that Rachael and I had an established interview relationship and that she clearly wished to continue, the final interview was undertaken.

The ambience of this final interview was filled with Rachael's expressions of wanting to share her experiences. She expressed love and tenderness, a little anger, but her overall realisation that even though she had finally *"lost"* Ted, she highlighted that: *"in contrast to the beginning [of caring for him], finally I was able to do 'the right thing' for Ted"*. At the end of the interview Rachael cried and told me that: *"this is the first time I have been able to cry, I didn't even cry at his funeral. I needed to cry. I know that you understand what it is like"*. I held Rachael's hand and we sat

together in silence. However, at this point I felt emotionally overwhelmed and wanted to stop myself from crying. So I dug the finger nails of my left hand into my left palm. A strategy which I had utilised during my working practice, particularly when attending the funerals of people with dementia or family carers with whom I had worked. This enabled me to concentrate on the physical pain, offering me a brief moment of respite from the emotional situation that we, Rachael and I, were experiencing. Before I said goodbye to Rachael, she confirmed that she had an appointment scheduled with the Alzheimer's Society Family Support Worker. I noted in my diary that I had driven home *"in floods of tears"* and that the typing of this final interview transcript was *"extremely difficult"*, but I also acknowledged that Rachael felt that she had been able to take back a degree of control at the end of her caregiving journey.

All of the forty eight interviews undertaken with the thirty study participants were completed by September 2011. Finishing the data collection period, I wrote in my diary that *"although this has been both a physical and emotional process, it has been an extremely pleasurable experience"*. I had been privileged to meet and interview family caregivers who had openly explored and shared their experiences of caregiving with me. It was now my role as researcher to effectively analyse and conceptualise the lived-experiences of these family caregivers within the landscape of dementia care.

3.6.5 Data Analysis and Experiential Events: 2012 - 2014

After Vasil's death I had quickly, without interruption, moved back into the throes of my research study and the completion of data collection. In April 2011, I had relocated from Northumbria University to work at the University of Edinburgh and had also transferred my PhD to a part-time course of study at this institution.[19] The beginning of the analysis of collated data, as well as the inclusion of field notes and my reflective diary entries, began in 2012. However, during this year I also experienced a third family bereavement, the sudden death of my maternal aunt (Sylvia). My Auntie Sylvia had undergone the removal of a brain tumour in the late 1990s and was extremely

[19] I was working as a research fellow on the Healthbridge Project and both my principal supervisor and new supervisor were staff members of the School of Health in Social Science, at the University of Edinburgh.

frail, but remained stoically undeterred and had always led a full and independent life. In her later years, because of her lack of mobility, she was helped by her son. I visited her often. After my Aunt's funeral and following an interruption in my research studies to assist my cousin in the task of clearing and preparing the sale of my Aunt's home, I was optimistically ready to resume my research at the beginning of 2013.

However, in February 2013 my father-in-law, Roland, was diagnosed with prostate, lymph node and stomach cancer. Roland had previously been diagnosed with *"possible*" Alzheimer's-related dementia in 2011. My mum-in-law, Sheila, was devoted to Roland and was caring for him at home. Initially, she had chosen to do this without any additional support from family members, or health and local authority care staff. Although my partner (Rob) and I kept in regular contact, we were not fully aware of Roland's progressive cognitive deterioration. Sheila, as with female members of PG1 and PG2 such as Jane (PG1/1), Maggie (PG1/16) and Alma (PG2/1), had initially chosen to undertake her caregiving journey independently, but had later sought assistance from family members and clinicians. It was only after Sheila was admitted to hospital following a transient ischemic attack whilst out shopping and Roland's subsequent confusion and delay in contacting family members, that his cognitive impairment was fully recognised. Roland spent the rest of the year in and out of hospital. This was a challenging period for my family, as we anticipated that given the fragility of Roland's health, that this would be our fourth family bereavement in two years. Roland died at home in October 2013 with Sheila at his side.

With the anticipated loss and then the final loss of my father-in-law I was reminded of the *"loss"* of my own father. Within this period of data analysis I often found the writing of new notes in my reflective diary, relating to my own thoughts and emotions, to be extremely challenging. Nevertheless, having undertaken the first reading and coding of the interview transcripts, as previously discussed, I was reminded of the study participants who had shared their poetry with me, and how they had found this format of writing to be an extremely beneficial strategy in expressing their emotions. This prompted me to write the poem *'Like a Leaf'* in memory of my father, Vasili Jacovitch Oleksuik, as presented on page (vi) of this document. As Denzin and Lincoln (2000) highlight, reflexivity can be cathartic and I certainly found composing this diary entry to be extremely therapeutic in representing my emotions during this period. This was also the

year in which I experienced my own health problems. I was diagnosed as having gallstones and physically I was in a great deal of pain; often looking rather yellowish *'around the gills'*. My surgery was delayed twice, but eventually I underwent my operation in November 2013 and took a two week break from my studies and work commitments to recuperate.

Resuming my studies in 2014, I was hopeful that my research journey would progress without any further personal events, but the year proved to be equally difficult for my family. We experienced two additional bereavements. The fifth bereavement was my father's dog, Ben, who was diagnosed with diabetes. Both the vet and my mother felt that it would be kinder, given Ben's age, for him to be euthanised. He was a lovable dog, bouncy in nature and Vasil had adored him. They had been in the garden together when Vasil died. Initially, I baulked at my mother's request of: *"Joanna, seeing that you are so much better at dealing with death than I am, would you take Ben to be put to sleep*?*"* I wrote in my diary that I was both reluctant and upset, but as with the two adult-giving daughters involved in this study, Joyce and Marie, I perceive myself to be a *"caring daughter"*, and so Rob and I took Ben to the veterinary surgery and said our final "*goodbyes*". On an emotional level I felt that with Ben's death this would end my last physical remaining connection with my dad. During this period, I documented in my diary that I often found myself in floods of tears. Especially when analysing the data transcripts relating to Harry (PG2/4/a-c) and the way in which he would often express and transfer his emotions via Lindi, the family's toy poodle.

The sixth family bereavement during this year was the death of our cat Lubha[20], who had been diagnosed as having feline dementia. Over the course of the year, Rob and I returned to the veterinary surgery on three occasions, anticipating that Lubha, like Ben, would have to be euthanised. The vet assured us that Lubha was not in any pain whatsoever and that it was our decision, although he strongly recommended that we take her home so she could end her days with us. Rob at this point was resolute that we should continue to care for Lubha and so we spent two months caring for her day and night, until the end of her life at 3.00 a.m. on 9th November. At 9.00 p.m. that evening I was scheduled to fly to London and then travel on to Brighton to

[20] Lubha is a diminutive name meaning *"little love"* in the Russian language.

present my PhD research at the 7th Dementia Congress the following day. On reaching Newcastle airport I found that the airline tickets I had purchased online were counterfeit. It was only then, standing in floods of tears at the check-in desk that I realised that the accumulation of caregiving, loss and bereavement I had experienced over the past six years had finally caught up with me. I therefore made the decision to return home and not to present at the Congress and offered my sincere apologies to Hawker publications.

Also in April 2014 my mother was involved in a road traffic incident, resulting in her having to have a twelve inch plate fitted in her upper arm and shoulder. This event had drastic repercussions for my mother's physical and mental wellbeing. Factoring in caring for my mother around my work commitments and my commute from Newcastle to Edinburgh, meant that when I was on campus for meetings with colleagues and students, my working day would often last up to eighteen hours. Hospital stays and innumerable appointments with the consultant, heart specialist, and various physiotherapists, as well as a protracted legal battle, continued throughout 2014, 2015 and into 2016.

3.6.6 Final Stage of the Research Journey: Experiential Events 2015 – 2017

After a third and much needed interruption, I felt emotionally robust to recommence my PhD studies in February 2015 and progress to the final stage of my research journey. During 2015 and 2016 I presented my research at international conferences. I had already begun the writing up of my research, yet due to the interruptions to my studies my final submission date had been extended several times. I was mindful that the need for a further interruption would only prolong my research journey and this was something which I did not want to happen. Since the commencement of my studies and the personal incidents and six family bereavements which I had experienced, I was reminded of the warning given to me in 2008 that: "*life sometimes impinges on our research".*[21] Life up until that point had certainly impinged on my research journey. Thankfully 2015 progressed without any further personal incidents.

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[21] A response given by a Professor working within the field of dementia studies when I stated that I wished to complete my PhD studies in four years.

Since the process of analysing data and the ongoing process of writing up my research I had still continued to write in my reflective diary, but my entries were not undertaken as frequently as they had previously been. Although one entry, at the beginning of 2015, reflected that: *"2014 was my 'annus horribilis'"*. Nevertheless, 2016 and 2017 proved to be even more of a challenge. My partner Rob, after twenty-four years of employment at an academic institution in the North East of England, was placed in a redeployment and then redundancy situation in August 2016.[22] I also experienced further health issues, not only relating to myself, but also my mum-in-law. Both of us were required to have emergency scans which, thankfully, proved to be clear. In October 2016 during a discussion with my PhD supervisors it was agreed that I would take another interruption in my studies. My mother was hospitalised with a serious chest infection just before Christmas of that year.

Again, at the beginning of 2017, I returned to my studies and wrote in my diary that *"hopefully the end is now in sight".* However, two other events occurred within the first six months. In May my mother had a hip replacement operation and had to stay in hospital for a protracted period of time because of a recurrent chest infection. I was her primary caregiver when she was well enough to return home. In June 2017, I experienced my seventh family bereavement, the death of my biological father. Although I had not had a close relationship with him for over forty-five years, his death had emotive repercussions. It brought back memories not only relating to my personal experiences, but also those of the participants involved with this study. At times I felt overwhelmed by change, grief, loss and bereavement. My thoughts often related to feelings of *"wading through mud"* and being stuck in a *"perpetual quagmire of grief"*, from which I would extricate myself, only to be pulled back into what Finlay (2002) describes as *"the swamp"*. Nonetheless, I continued with the final part of my research journey. Only this time I did so without further interruptions to my studies.

[22] After six months Rob finally secured another permanent post at the same institution in February 2017.

3.6.7 Reflexive Summary

Overall, I found writing in my reflective diary to be extremely beneficial, although at times equally difficult to undertake and to read. From a research perspective, as Mauthner and Doucet (2003) suggest, I utilised my notations as an additional resource of interpretation relating to the experiences of the study participants. Particularly with regard to the experiences presented by the two adult-caregiving daughters Joyce and Marie which, at times, appeared to parallel aspects of my own life. Nevertheless, the advantage of keeping a reflective diary, as posited by Roller and Lavrakas (2015), had offered me an opportunity to undertake a continual internal dialogue of critical self-evaluation. I was able to acknowledge and work with my fore-structures of understanding '*fore-having', 'fore-sight'* and *'fore-conception'* associated with my practical familiarity and historical perspective of working with family caregivers of people with dementia. In doing so, I was able to highlight my collective understanding of dementia in relation to positive or negative influences which may influence this research study. What I had not anticipated was that my subsequent understanding would also position me within my own dementia caregiving landscape, which had been clearly highlighted by Rachael. In doing so, my sense of self changed.

Reflecting on my positionality, metaphorically I find the analogy of reflexivity as proffered by Finlay (2002) of *"negotiating the swamp"* to be extremely pertinent. At times, particularly after experiencing bereavements in my own family which were dementia related, I truly felt that my intersubjective understanding was challenged. However, during my research journey I was continuously mindful, as Linda Finlay advises, of not falling *"into the mire of the infinite regress of excessive self-analysis and deconstructions at the expense of focusing on the research participants*" (Ibid: 212). Finlay further argues that the useful application of reflexivity relates to a balanced link between personal disclosure and the relevant analysis of study data and I certainly found this to be helpful.

At the commencement of the analysis period of this study I had expressed my wish in becoming fully immersed with the research data, enabling me to elicit the true *'essence'* of the lived-experiences of the thirty participants involved with this research study. Nevertheless, at times I felt that during this and the subsequent processes of the research journey I had become totally

submerged within a *"muddied*" landscape. Disentangling my own experiences vis-à-vis to those of the study participants relating to change, grief and bereavement was problematic, but I feel nonetheless achieved.

3.7 Review of Chapter Three

In conclusion, I am again drawn back to Steinbeck's quotation offered at the beginning of this chapter before moving on to discuss, in chapter four of this document, the dementia caregiving experiences and the co-created exploration of the journeys undertaken between the thirty study participants and myself. Reflecting back, I discuss in part one that I had '*good and sufficient reason for going'*; this was the initial aim of this research study to explore the entire dementia care-giving journey of family caregivers from dementia diagnosis to final bereavement in relation to anticipatory grief and loss. A research topic which has, to date, not been fully addressed by other research studies. In part two, I discuss the methodological routes considered, although not undertaken and an explanation as to my reasons why. In part three of this chapter I highlight my '*direction*', my methodological approach being a hermeneutical phenomenological interpretation of the research data, as well as my *'skills-based-equipment'* in the application of my counselling training during the process of interviewing the participants involved in this research journey. In part four, I '*map out'* the research journey, with the assistance of my Alzheimer's Society colleagues who acted as '*gatekeepers'* in the recruitment of a convenience sample of thirty study participants (members of PG1 and PG2). In addition, I present the documentation provided to all who were involved in this research study.

Part five begins with the step-by-step process of analysis, beginning with the enumeration, coding and a brief synopsis relating to all of the participants. Subsequent steps offer a description of analysis, conceptualisation and reconceptualisation of thematic data associated with the adaptation and application across the entire dementia caregiving landscape of the theoretical framework as offered by Fulton and Fulton (1971) and Fulton and Gottesman (1980). In the theoretical development of data my interpretation of caregiving experienced by all of the participants placed them at the very centre of three inter-related and overlapping thematic strata within the landscape of care. Firstly, sub-themes relating to the psychological day-to-day aspects of caregiving

experienced within the expansive and foundational '*topographical landscape'*. Secondly, the '*communicative landscape'*, appertaining to points of the journey where the majority of participants expressed significant inter-personal communication with others had occurred. The third stratum represents the '*orientation of self and wellbeing within the landscape'*. This final layer of the stratified landscape of care is associated with strategies and routines currently or previously undertaken by some participants, although not all, during the course of their caregiving role.

However, the dominant conceptualisation which emerged during data analysis was the interpretation of three interconnected yet fluctuating schemas of self, representing participants' experiences of *me-self, relationship-self* and *caregiving-self* across the entire caregiving journey. In the final part of this chapter I offer a reflexive view as to the location and orientation of myself in response to personal experiences which informed this study and aspects of the research which I found to be challenging.

In chapter four of this document I utilise verbatim quotations to describe and illustrate the fluctuating perceptions of self and the collective emotional experiences of the members of PG1 and PG2 within this stratified dementia care landscape.

Chapter Four

Fluctuating Perceptions of Self within the Landscape of Dementia Care

4.0 Introduction

> The wonder (is) that a world is worlding around us at all, that things are and we ourselves are in their midst, that we ourselves are and yet barely know why we are, and barely know that we do not know all this (Heidegger, 1962: 83).

This chapter is divided into three sections, part one, the '*topographical landscape*' is followed by parts two and three, the '*communicative landscape'* and '*orientation of self and wellbeing within the landscape'*. Each part is sequentially presented in a thematically layered format. Through which interpretation and re-interpretation builds and formulates a stratified dialogical tri-dimensional representation of participants' emotional and physical responses to change, grief and loss within the dementia caregiving landscape.

Intersecting with this layered landscape is the emergence of a conceptual framework which involves three interconnected yet fluctuating schemas of self and being experienced by participants, whilst caring for their family member. The first schema is the individual *me-self*, which relates to the participants' perception of their core self and envisaged sense of self. The second schema, the *relationship-self* illustrates the bonded connection between themselves and the cared-for spousal partner or parent, as well as other family members and care workers. The third schema is the *caregiving-self*, associated with the acquisition and undertaking of their role of familial caregiver.

The presentation of extracted quotations from collated data relating participants' experiences of caregiving include the emotional expressions of the non-linear '*grief-tools*' as outlined by Kübler-Ross (1970) and Kübler-Ross and Kessler (2005). These are *'acceptance'*, *'anger'*, *'depression (feelings of isolation)'*, *'denial'* and '*bargaining'*. In addition, other expressions of emotion emerged as sub-themes within the *communicative landscape* and reflect participants' perceptions of *'love'*, *'guilt'*, *'empathy'* and '*connectedness'*.

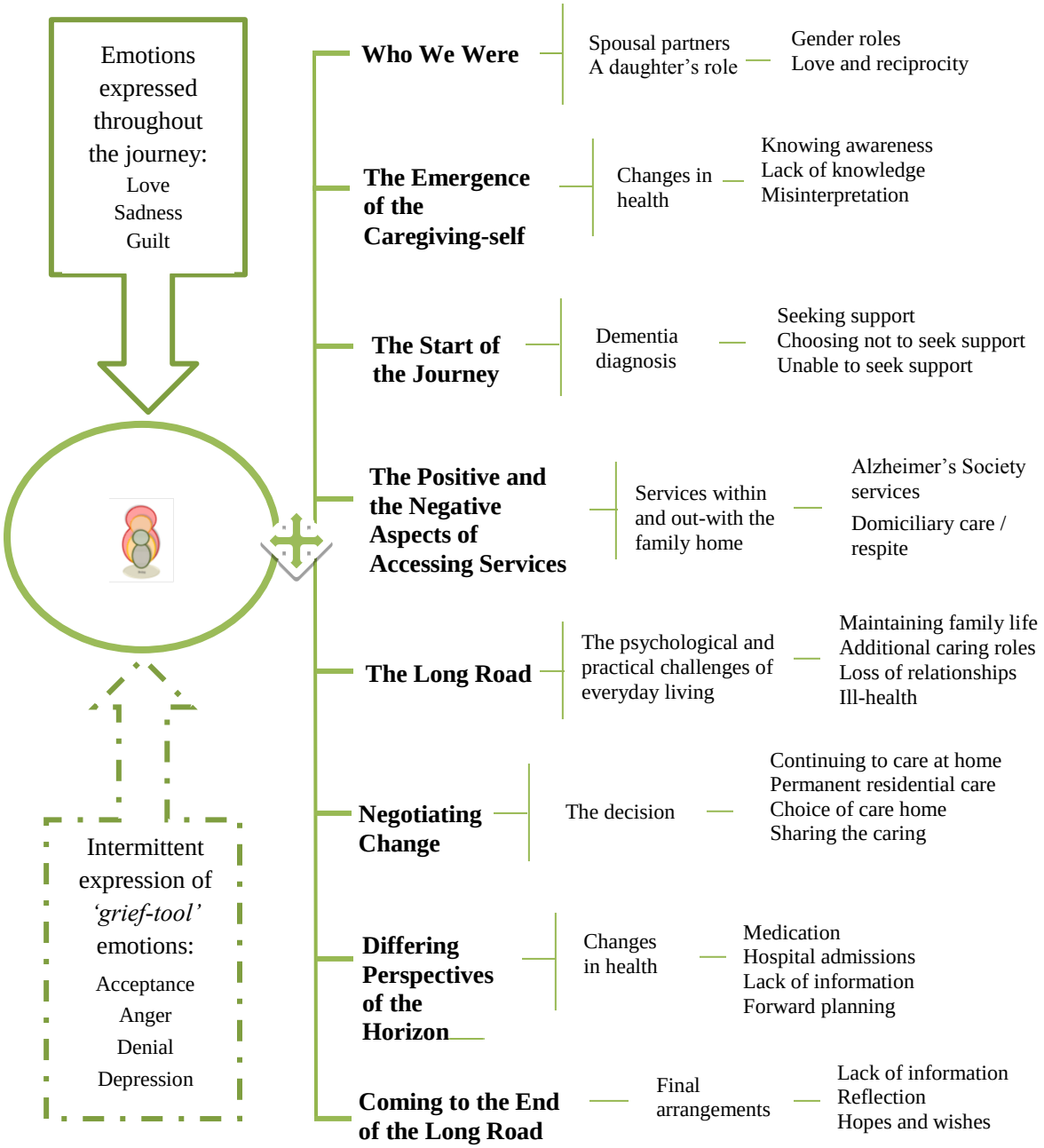
4.1 The Topographical Landscape

At the beginning of the single interview (with members of PG1) and the initial interview (with members of PG2), each participant spoke about an expansive and chronological landscape encompassing their experiences of caring for their family member living with dementia. Participants highlighted periods relating to pre- and post-diagnosis, as well as their experiences of accessing support services within and out-with the family home. In addition, participants emphasised the beginning of a protracted middle period. A period which participants experienced as occurring one or two years after the diagnosis of their family member and perceived by participants of both groups as being "*the long road"* of their individual caregiving journey. This extended caregiving period, undertaken within the family home as well as a continuation of accessing appropriate and available support services, was reported by participants as lasting between two to twelve years. Participants also spoke about the consideration and subsequent decision of their family member entering or not entering permanent residential care.

Given the retrospective and current perspectives of members of PG1 and PG2 respectively, there were divergent views offered by participants of both groups with regard to the palliative and end of life care periods of their caregiving journey. Members of PG1 were reflective, describing these periods as being experienced in the recent past. In contrast, the current perspective of members of PG2 appeared to remain firmly rooted within "*the long road"* period, with their anticipation that the palliative and end of life aspects of their caregiving journey would be experienced in the distant future. Participants of PG1 also explored the final loss of their family member, as well as their post-bereavement experiences of their individual caregiving journeys. Whilst participants of PG2 highlighted perceived and anticipated outcomes relating to their current and continuing caregiving role.

The thematic map outlined in Figure 7 illustrates the topographical foundation and sub-themes relating to the stages and events of the psychological activities of the participants' journeys. At the beginning of the single interview with members of PG1 and the initial interview with members of PG2, participants began by reflecting on an introductory description of a "*who we were*" period. Within this period participants not only spoke about themselves in relation to their schemas of

Figure 7 Themes within the Topographical Landscape



me-self and *relationship-self,* but also their connection to the cared-for-person and other family members.

4.1.1 *"Who We Were"*

The exploration of the "*who we were*" period of their individual journeys offered by the twenty eight male and female spousal participants of PG1 and PG2, involved looking back to past horizons spanning forty to sixty years of married life. Initially, participants' sense of self and being related to their experiential perception of their schemas of *me-self* and the development of their *relationship-self* with their spousal partner. Also emphasised during this period were the gender specific caregiving roles undertaken within their early marital relationship, which participants reflectively returned to during the course of the interview process to highlight their perception of the schema of *caregiving-self*. In doing so, they perceived and acknowledged the reciprocal change from initially being cared-for by their spouse, to becoming caregiver within their marital relationship.

At the very beginning of our single interview, Susan, a petite and energetic woman spoke about being married to her husband, Roland, for over sixty years. She described their marriage as being "*extremely happy and full of love*", but also added that prior to Roland's dementia diagnosis she regarded her self-identity as being the spirited and leading partner within their marital home:

> Look, I've got a picture of us on this [mobile phone]. Aye, "*Little and Large*", he's a big lad … sorry, <u>was</u> a tall lad, 6'2" in his bare feet and me, only 4'11"… in heels. But I was always the firebrand in family though (PG1/5).

However, Maggie in contrast to Susan and other female spousal caregivers spoke about her perception of a mutual and shared marital relationship with her husband, Si. Nevertheless, she also acknowledged her sense of *me-self* by stating her wish in continually trying to maintain a sense of personal independence within and outside of their marital relationship:

> You see, Si and I … we were always equal partners, but I was always one of those "*women's libbers*" (*laughing*) (PG1/16).

During our single interview, Patricia stated that she had been married to her second husband, Nigel, for over forty-five years, prior to his death in 2007. As with other male and female spousal

participants of PG1 and PG2, Patricia highlighted that for the majority of her married life there had always been a clear delineation of roles within their relationship. A relationship in which she overwhelming felt cared-for by her spousal partner:

> He was a Desert Rat during the war. I was twenty three when I first met him. You see Nigel was older than me, much older. Eighteen years in fact. He was always a soldier and gentleman. He looked after ME. …He always looked after me and always looked for the good in everybody (PG1/10).

Brenda also spoke about how her husband Don, prior to receiving a diagnosis of Lewy Body related dementia in 1999, had also taken the lead role within their marriage:

> We went everywhere … [names of various cities] and all those places in the Middle East. I had never been out of [name of town] until I met him. He decided everything then. I just left everything to him (PG1/15).

Following on from this reflection of being cared-for by her husband, Brenda quickly moved the conversation forward from her far distant past, to her more recent past in expressing her thoughts relating to the post-dementia diagnosis period of her journey. She stressed her sense of *caregiving-self* and the subsequent acquisition of her new role:

> I did things and he did things … It was odd when I had to take over everything, after the dementia [diagnosis]. It just wasn't me. Everything was just so new. I'd never done it before, the money and stuff (PG1/15).

In exploring the "*who we were*" period male participants of PG1 and PG2 also talked about early experiential aspects of married life. Older male participants, Brian, George and Burt for example, spoke about being in the Royal Navy when they had met their respective wives. However, during the course of the single interview with George he reflected on this distant period of his life as enabling him to empathically recognise the change within his marital relationship. This had occurred in his more recent past, when his perception of self changed to becoming a caregiver for his wife Mabel and his final loss of their relationship:

> She was at home with the children and did everything. Then, when she was ill and I was caring for her it made me think what it must have been like for her when I was

> away at sea when we were first married. She did everything. God I miss her (*sighing*) (PG1/13).

Burt also reflected on the "*who we were*" period to emphasise his perceived transition from being cared-for by his wife May, to becoming caregiver to her and as with other male participants his acceptance relating to the practical necessities in undertaking his new role:

> Before May was diagnosed with it [dementia] she used to make lovely meals, curries and what not, I couldn't even boil an egg. The kitchen was hers; she wouldn't let me do anything. I soon had to learn mind you. Towards the end [of her life] I could make the dinners. Nothing fancy you understand, but I needed to look after her. I was caring for her now (PG1/17).

All of the twelve male participants of PG1 and PG2 acknowledged that during the early part of their married life the day-to-day activities of caregiving within the family home were undertaken by their respective wives. Nevertheless, they accepted their transition to their role of caregiver. However, only two female participants, Patricia and June, spoke about their acceptance of becoming the primary caregiver for their spousal partners, but their reluctant recognition of the acquisition of being referred to as a carer. Patricia again reflected on the "*who we were*" period by accentuating her perception with regards to her fluctuating schemas of self by angrily stating:

> They [clinicians and care staff] always referred to you …to ME, as Nigel's carer. I wasn't his carer; I was his WIFE. OK I was "*Patricia the secretary"* before I got married, but after that I was "*Nigel's wife"*. Nigel was MY husband (PG1/10).

In our first of three interviews, June echoed Patricia's perception that the label of carer was incongruous to her perception of her schemas of *me-self, relationship-self* and *caregiving-self* with regards to her husband Sid:

> To the boys I was "*mam*" and he was "*dad*" – well step father actually, but they always called him *"dad"*. And I was his wife. Not Sid's *"carer"* like the doctor always says. CARER! Of course I care, he is my husband. Calling me "*the carer*", it was as if Sid no longer cares for us [herself and the family], but he does. He doesn't say it now, like "*I love you"* and all that, but I know that he does. You do don't you? (PG2/7/a).

June expressed her accepted awareness of the loss of her husband no longer being able to verbally express his love to her and to other members of the family. Yet her perception of her schema of self remained firmly within a reciprocal and loving marital relationship.

Other beginnings within this period of the dementia caregiving journey also highlighted day-to-day expressions of love between spousal participants of both groups. Margaret, a woman in her mid-eighties for example, who had cared for her husband Joe at home with full support from her two children, began our single interview by emphasising her interconnected *relationship-self* with her husband:

> We were childhood sweethearts. We met at school, I was 14 and he was 15 *(smiling).* There was no other man for me. He looked after us [the family], he took care of us. It was always him … just me and him, and the bairns (sic) of course. We had a lovely family, two beautiful children, because he was a lovely, lovely man. …MY man (PG1/4).

Bill, during the first of our three interviews, reflected on his perception of his schema of *relationship-self* and *caregiver-self* in emphasising the reciprocal aspect of now caring for his wife. Who, given her advanced-stage-experience of dementia, had lost both her physical mobility and verbal communication skills eight years prior to our initial interview:

> Funnily enough we met at a TB place in Northumberland … a sanatorium. You see we both had tuberculosis when we were in our early twenties. Mary was a bit younger than me of course. Well she cared for me up there. I was in a bad way you see (PG2/10/a).

He also acknowledged that with the assistance of an extended care package, facilitated by local authority care workers, he felt that he was able to continue his caregiving role within the family home. Later during this initial interview and also again in interviews two (b) and three (c), Bill again reflected on this period of *"who we were"* in his repetition of his experience of currently being the primary caregiver for his wife:

> You see she did it for me then and I know that she would have done it again if the tables were turned… I know that she loves me for doing this. You can see it in her eyes. She blinks and smiles, which is great (PG2/10/a).

Other aspects of family life were explored by participants during this period, especially with regard to their experiential interpretation of their *relationship-self* to not only the cared-for-person, but also with other family members. Jane, for example, whilst reflecting back to her far distant past quickly moved the conversation forward. She highlighted that although she and her husband, Norman, had both worked full time when their children were young, they had enjoyed lots of family time together:

> The weekends were ours. We'd all pile into the car and head over to the Lakes or somewhere in Northumberland. We'd get the kids out into the fresh air; they didn't have any of these computer things then like they do now. It was good to get out, all together (PG1/1).

Nevertheless, Jane completed her reflection by moving the interview conversation to a more recent part of her journey with regard to her experiential grief in relation to the loss of Norman's cognitive abilities and his diagnosis of early on-set dementia:

> …Yes, none of these computer things… although Norman was… always good with computers … *aye*, good then (*pause*). He was so young when it [dementia diagnosis] happened. …So sad (*sighing*) (PG1/1).

For other spousal caregivers and their families additional journeys had physically been undertaken further afield within the *"who we were"* period. Pointing to a family photograph taken in 1972, Linda spoke about how she, her husband Henry and their children had emigrated from the UK in the 1970s. Even though Henry had been visually impaired since birth, this had not deterred him from pursing a demanding career and then how the reality of their "*wonderful life*" had suddenly been interrupted:

> He had always been partially sighted, but that <u>never stopped</u> him doing what he, <u>WE</u>, wanted to do. As I said, we lived abroad because of his work. For many, many years … it was a wonderful life, a wonderful time – the snow and the kids. But this, <u>THIS</u> [dementia] stopped him. We had to come home (PG1/14).

Other participants of PG1 and PG2 who did not have children, such as John, Patricia, Brian, Burt, and Alex, spoke about annual holidays abroad to sunnier climates. John shared memories relating

to his *relationship-self*, highlighting trips that he and his wife May had enjoyed by expressing feelings of "*us and togetherness*" during this period:

> It was just "*us*", no kids. We went everywhere together. May and I travelled all over together, we travelled down to Spain by car, …that was hot and to Austria, we went everywhere together. Venice, Innsbruck … France everywhere, everywhere together (PG1/3).

Yet in moving forward to the point of May's dementia diagnosis, John expressed his recognition of his anticipated loss and acceptance of being unable to plan and experience similar events in the future:

> Of course … once *err*… she was told, we were told [dementia diagnosis] that had to stop. I knew that (PG1/3).

During the course of the interview process, spousal participants of both PG1 and PG2 continually looked back at this period in expressing it as a loving and foundational representation of their *relationship-self* with regard to their spousal partner. However, caregiving and the perception of self-identity associated their schemas of *me-self*, *relationship-self* and *caregiving-self* during this introductory period were not perceived by male or female spousal participants as being the definitive representation of marital obligation. As with Bill, reciprocity of care was viewed as an acceptance of their previous and current circumstances, undertaken as an expression of continuous love for their husband or wife.

Family, love and reciprocity relating to their childhood and familial experiences during the "*who we were*" period were also explored by Joyce and Marie, the two adult-daughter caregivers involved in this study. Joyce, part of the father and daughter caregiving dyad of PG1, who had previously supported her father Bob in caring for her mum Alice, began by stating her perceived view of her schemas of *me-self* and her interconnected *relationship-self* with her parents:

> My mother was a wonderful mam, the best that anyone could wish for (*smiling*). We, my brother and me, had a lovely childhood with her and dad. We were much loved and cared for (PG1/11).

Joyce then explored her sense of self within a collective timeframe of past, present and her anticipated future by stating:

> Being a boy, I think that our Charles [name of brother] would often get away with "*blue murder"*. He stills gets away with murder, he's never around and he's like the "*prodigal son".* And me being the only daughter, I think that I always had to be "*the good girl, the caring child"* (*laughing*). But I wanted to care for mam. I always wanted – I want to continue to help dad …That's why they moved to the house next door (PG1/11).

In contrast to Joyce, during our first of three interviews Marie spoke about the challenging relationship she perceived she had and was continuing to have with her mother. As part of the father and daughter caregiving dyad of PG2, Marie is currently caring for her mother, Kathy, who has been living in permanent residential care for four years prior to our initial interview. At the very beginning of our first interview Marie accentuated her perception of self as being a deep-rooted and protracted role reversal regarding her relationship with her parents. Her sense of *me-self* and *relationship-self*, particularly associated to her familial attachment towards her mother was personified as always having been a '*parentified*' child. A relationship in which she felt she had always undertaken the emotional and functional roles, which are typically considered and performed by the parent.

Tearfully, Marie began our exploration of her caregiving journey by expressing her perception of her schema of *me-self* by saying:

> I feel that I was conditioned to care from a very young age. You see mum drank, always did, ever since I can remember. I think that it started after the death of her mother when I was two years old. My dad hardly ever touched the stuff, but she had bottles of alcohol everywhere, in the kitchen, in the garden shed. I would hide the empty bottles from dad. I think that he knew, but he just denied it. Like now - he talks about mum having "*memory problems*". NO! She was diagnosed with a mixture of dementia, Alzheimer's and possibly alcohol-related dementia in 2001. Well he just won't see it. I don't prompt him, because that's how he deals with it (PG2/5/a).

Marie continued by stating her perception of a perpetual lack of reciprocal love from her mother and her awareness of always having to undertake covert action in trying to protect her father, Harry, from the reality of her mother's ill health:

> You see *Jo* [directed to me]; I don't think that she ever loved me like a mother should. Dad was always there for me and loved me. I think she always hated that. But I LOVE her. She's my mam and dad needed, he needs my help. He just can't deal with it. I am their only child (PG2/5/a).

Although Joyce and Marie had diverse experiences of their schemas of self with regards to their *me-self* and *relationship-self* within the "*who we were"* period, both fluctuated from this point during the interview process to explore their perceived future horizons with regard to their sense of *caregiving-self* vis-à-vis their *relation-self* with their own spousal partners.

In reflecting on her current reality of caregiving, Joyce wearily stated:

> I don't think that I can go through it all again with dad, caring for him … His health is deteriorating rapidly… Not his memory you understand, but his physical health and I have Ian [name of husband] to think about. It would be just too much. I can't ask Ian to go through it all again with dad (PG1/11).

She then paused to reflect and then asked a rhetorical question relating to the continuation of her schema of *caregiving-self* by enquiring:

> … But I have too, don't I? (PG1/11).

In her reflection of this question Joyce's mood rapidly changed with regard to her schema of *relationship-self* and her perceived view of never having received support from her sibling. She angrily asked another rhetorical question:

> And in all …and in ALL of this *Jo* …did you know I have a brother? (PG1/11).

As with Joyce, Marie during the early part of our first interview also moved forward in the exploration of her caregiving journey to talk about her current and anticipated future regarding her sense of self and her perceived continuation of providing care and support to her parents:

> You have to help your parents … well you don't have to …but you just can't walk away either can you? But it is TOO much for me and Dan [name of husband]. Neither of us have any siblings you see. But we just don't have time for us …for each other (PG2/5/a).

In their reflections of this period both Joyce and Mary highlighted an emotional and dichotomous view of their schemas of self. Nevertheless, their perception of their schema of *me-self* and their anticipated continuation of wishing to undertake their role of *caregiving-self* for their parents highlighted their realisation of the potential psychological effect with regards to their own marital *relationship-self* with their respective spousal partners.

4.1.2 The Emergence of the Caregiving-self

Moving on from the "*who we were*" period participants of PG1 and PG2, whether they were spousal or adult-daughter caregivers, also emphasised other health or perceived age-related issues experienced by their family member during the pre-diagnosis period. Participants expressed differing experiences relating to a knowing awareness, lack of knowledge or their misinterpretation relating to the gradual loss of cognitive skills being experienced by their family member.

For example, Maggie talked about her husband Si and how she became aware of the development of his cognitive difficulties after he had undergone a hip replacement operation in the early 1990s:

> Having Alzheimer's is not just the only problem, because people with Alzheimer's have other health problems, before all this (dementia diagnosis). For instance, he [Si] had to have a hip replacement and he had an aneurysm… even before we knew about it [dementia]. But I KNEW that this [dementia] was different (PG1/16).

In the exploration of his dementia caregiving journey John continued to talk about holidays spent with his wife, May, but then he spoke about the pre-diagnosis part of his journey. He highlighted various crises relating to his concerns regarding May's health and his anticipated loss of his *relationship-self* and his overall sense of *"us and togetherness"* within their marriage:

> We were booked to go to Cyprus on holiday; we'd been before you see. But she came home one day and her face was all bloody and that, and I said "*have you been mugged*?" She had tripped and fallen in the village. Then a few weeks later, down

> at the coast, she tripped and fell and cut her face again. We went through to [name of village] to see our Katie [name of niece], and I said to myself *"I've got trouble here and I don't know what it is",* I am going to see the doctor. Of course May didn't want to go at first. You have to understand it was just US doing things together (PG1/3).

Additional health related issues experienced by family members were also explored during the pre-diagnosis period, which participants had felt concealed the true extent of the development of cognitive difficulties being experienced by their family member. This was expressed by participants as being confusing, which resulted in not knowing how to differentiate between previous symptoms of ill-health and the beginning of dementia. Joyce for example stated:

> Because Mum had a brain haemorrhage, *hmm* …in 1998, she came out of hospital and we were told that she wouldn't have all her faculties anyway. Consequently, she didn't speak to us and she didn't always know us, but gradually over the next few years she came back to knowing who we were with the help of speech therapy, which she had for two years. So I suppose with her having the haemorrhage that we didn't notice her failing memory, because in the two years after the haemorrhage and her "*getting better*" her memory wasn't good anyway. So I think our journey was different to a lot of people (PG1/11).

In contrast to Joyce, Rachael during our first of three interviews angrily expressed her total lack of awareness and subsequent confusion with regard to a traumatic and significantly distressing event involving her husband Ted. Unlike Ted's work colleagues, Rachael had been unaware of any issues relating to Ted's cognitive ill-health prior to this event:

> I am just bloody angry … It's [dementia] has taken everything, everything! We had such plans for after he …no WE retired. But he went out to work one morning and never came back. Never came back to the house, to me (*sighing*). Things had been happening at his work …for a while apparently. Arguments with other lads [colleagues] and Ted had become angry this day, lashed out at another workman and the police had to be called. He became violent – well, because of that he was sectioned … you know mental health (sic). I don't know how, how he ended up in that place [name of assessment unit]. Well that was it *Jo*, – that was "*the start"* (*deep sigh*). I didn't know what was to come (PG2/2/a).

Not only did Rachael experience confusion and lack of knowledge associated with the health issues being experienced by her husband and what may happen in the future, but also her perception of self changed irrevocably within hours of this pivotal and detrimental incident. Her schema of self rapidly fluctuated from her marital *relationship-self* with Ted, to her perception of having to accept her new role as caregiver for her husband.

The unanticipated experience of dementia, especially with regard to a lack of previous knowledge was also indicated by participants, particularly by older male participants of both groups living within rural communities. Dave, for example expressed his experience during this period and the deterioration of his wife's memory by stating:

> I knew nothing about it … Alzheimer's and all that. I thought that it was just Moira's age. I couldn't pin point it [changes in Moira's health], but we just got on with it (PG1/6).

Harry, who is currently caring for his wife Kathy with the support of his daughter Marie, also echoed his unanticipated knowledge of dementia during the pre-diagnosis period:

> Kathy has got memory problems you see…I suppose Marie [daughter] has told you this. I thought it was just our age, we are both getting on and your memory goes as you get older I think. Marie has been a great help, always has. At first she got Kathy to the doctors (PG2/4/a).

The pre-dementia diagnosis period was expressed by participants as occurring across varying timeframes lasting between one and three years, or as a definitive event prior to the actual dementia diagnosis being received and the perceived start of their caregiving journeys. Nevertheless, participants' schemas of self began to fluctuate between their established *me-self,* their core self-identity of who they perceived themselves as being, their *relationship-self* to their cared-for family member and to the future acquisition and acceptance of their role and schema of *caregiving-self*.

4.1.3 The Start of the Journey

The dementia diagnosis period of the journey specifically related to three differential perspectives expressed by participants. Those who actively chose to seek support and confirmation of the diagnosis in response to their awareness of their spousal partner or parent beginning to experience

loss of memory and other cognitive difficulties. In contrast to participants who after receiving a diagnosis expressed that they consciously chose not to seek additional support. Whilst the majority of older male participants highlighted that post-diagnosis they were unable to seek support.

For example, Alan[23] had previously cared for his wife Ethel and during the course of our single interview he talked about *"the start"* of his caring journey as being a definitive event. This he stated had been an abrupt, almost overnight loss of skills which Ethel had previously possessed. In particular, this related to Ethel's proficiency for dressing making and handicrafts. With the occurrence of this incident Alan began to anticipate the ambiguity of their future:

> Before the Alzheimer's she could do anything, like sewing. Look *(pointing around the room to three sewing machines, two knitting machines, bolts of material and five plastic shopping bags containing balls of wool).* She made all these, the curtains and cushions, everything, the lot! So we went to see the doctor and he said that he thought that it was coming around to the dementia (sic) and I thought to myself "*this is the start and things are going to happen*". Of course *Jo*, I didn't know then what I know now (PG1/2).

As with other participants, Patricia stated that it was a gradual realisation relating to memory loss and the acknowledgement of behavioural changes displayed by her husband that had prompted them visit their GP. Although she echoed the experiences of other younger female members of PG1 and PG2, by stating that prior to the confirmation of Nigel's diagnosis she had possessed limited knowledge of dementia and dementia medication:

> He NEVER had anything wrong with him, ever. But, then he became quite short of breath. It was asthma, but he wouldn't take his medication and at one point he was taken to hospital. Two years after that was when the Alzheimer's started and at first I thought that it was just memory loss. But one day, you see he was a water colour artist, I found a mark on his bed on the yellow bed sheet and he had mixed the perfect match with the paint onto the bed sheet. When he did that I thought "*that's not right*". We went to the doctor and he started having tests for

[23] At the beginning of the single interview untaken with Alan he informed me that it was the 2nd anniversary of his wife's death. Nevertheless, he expressed that he still wanted to undertake the interview in memory of his wife Ethel and how he felt that his experience may also *"help other families.*"

> Alzheimer's and I thought that perhaps he could have medication, which I had heard about, and sort of knew that it wouldn't cure him, but that it would help. It was ... *hum*, not Aricept, the other one - Reminyl … that kept him right for a couple of years (PG1/10).

In contrast to Patricia and other participants, Jessie talked about her husband Barry not wishing to attend an appointment with their family doctor and how this decision had led to devastating repercussions for Jessie being able to seek initial support for them both:

> Looking back it all started ten years ago, before he finally got his diagnosis. He had retired early, he had his own business you see and we were financially secure, but then …and he started to forget things. I made an appointment for him, but he wouldn't go to the doctors, just wouldn't go. He'd always been the quiet type, a loner really and had never done anything in the house, so the children didn't know or could see any difference. He was just '*dad*'. But I knew. I <u>KNEW</u> (PG1/18).

Nevertheless, unlike Jessie, female caregivers such as Jane, Maggie, and Alma whose spousal partner had received a diagnosis of dementia, expressed that initially they had not wished to seek external support outside of their own marital relationship. Jane offered an example of her decision of wishing to protect her children during this period by stating:

> At that point, the boys didn't need to know. They live locally in the village, but then, at that time I thought that they had their own lives, families and work (PG1/1).

Again, in highlighting her independent approach with regards to her relationship with her husband Maggie stated:

> In even the best of marriages, you know, you have your differences. But we were really true to each other …and this is what I found out when he, when we retired. Si started to have… to show signs of forgetfulness. I thought "*Oh, he's always been a forgetful professor type"* you know… and ignored it for a couple of years. I really kept it to myself. Didn't even tell the children, they were up and away by that time of course. They had their own lives and I thought … "*well, if it is Alzheimer's", I can…* you know… "*I can cope*". I did cope … I just kept it close between "<u>*us*</u>" (PG1/16).

The sentiment of coping within the marital relationship was repeated by Alma[24] who stated:

> Of course, after Tom was diagnosed with it [dementia] I knew where to go for help. The consultant gave me lots of information and the branch [Alzheimer's Society] is just up the road. But I thought that there would be time for their involvement in the future. For now … well then you understand …I wanted it to be just me and him. I needed to come to terms with it (PG2/9/a).

Although Jane, Maggie and Alma had individually accepted their new schema of self and their role as caregiver to their respective husbands, they initially did not wish to seek additional support from either family members or external services for two interconnected reasons. Firstly, even though all three women expressed that they had a close and loving relationship with their adult children, they felt that they did not wish to impose on their family members at this initial stage. Secondly, they also had an awareness of the possible future outcome of the dementia caregiving journey and in doing so conveyed their wish to maintain their relationship with their spousal partners. Their schema of self related to their wish of being able to sustain aspects of their "*who we were*" period of their married life for as long as they were able to, prior to their anticipated loss of what their relationship had once been.

However, older male caregivers of both groups, for example George, Roy and Alex, echoed the encounters experienced by other caregivers and family members (the cared-for-person) who had received a diagnosis of dementia, but who were not, at the time, given further information. In contrast to female participants such as Jane, Maggie and Alma, they subsequently felt that they were independently left to cope with their caring role. Alex exemplified this experience by reflecting on his experience:

> We'd been to the doctor for something else, I can't remember what, but because our doctor is in [name of city]; we went to see a psychiatrist at [name of hospital]. That's where Sheila [wife] … where they diagnosed her. And after she was

[24] Alma was a participant member of PG2 who was scheduled to be interviewed on three consecutive occasions over an eighteen month period, but due to the anticipated death of her husband Tom, she was interviewed only once. On first meeting with Alma she clearly stated that she wanted to be interviewed as she felt that it would *"help other carers*" in the same situation.

> diagnosed, she was transferred to [name of unit]. We went there, and they did a test – and that was it, NOTHING. Absolutely nothing from them and I didn't know what to do and so I left it for a couple of years. I just got on with it… caring for her and that (PG2/8/a).

Post-diagnosis none of the participants of PG1 or PG2 expressed their denial of their family member experiencing cognitive loss. However, older male and female caregivers of both groups often referred to "*memory loss*" being experienced by their spousal partner, or were unaware of the specific type of dementia diagnosis their family member had received. Nevertheless, all participants articulated their perception of their schema of *caregiving-self* during this early period, as being an accepted and reciprocal extension of their loving *relationship-self* with their spousal partners or parent. This period was highlighted as the beginning of their full awareness of not only the emergence of their *caregiving-self*, but also of the requirements and anticipated challenges of their role as caregiver.

4.1.4 Positive and Negative Aspects of Accessing Services

As a prerequisite of their involvement in this research study, all of the participants of PG1 and PG2 were still in contact with their local branch of the Alzheimer's Society. They emphasised that at some point during the early part of their caregiving journey they had sought and had been given the opportunity by Alzheimer's Society staff to access services, where available, for either themselves and/or their family member. For example, attendance at an Alzheimer's day centre for their family member with dementia was highlighted by participants living within urban communities. Each Alzheimer's Society branch, whether they were located within an urban or rural area, offered practical information, one-to-one contact with support workers and peer support group meetings for family caregivers. Nevertheless, transport difficulties associated with their ability to access services and groups on a regular basis by either themselves and / or their family member, were indicated by older male and female members of both groups residing in rural communities.

Female participants, with the exception of Jane, Maggie and Alma who had chosen not to access support services at earlier stages of their caregiving journey, had previously been offered and had accessed services facilitated by their local branch of the Alzheimer's Society such as peer support group meetings for family caregivers. Within urban communities additional services included day

centre attendance for their cared-for family member. Although there was often a waiting list of several months, prior to their family member being able to attend the service on a regular basis. In our first of three interviews, April talked about the positive aspects for both her husband Billy and for herself in his attendance at the Alzheimer's Society day centre:

> Billy used to go out three times a day for a walk with Tina [name of dog]. Well she took him out and she always brought him back (*laughing*). But the girls [staff at the branch] offered him the chance to go to the day centre each week and that helped. He enjoyed it. He liked the company and was always *"brighter*" after he came back. But of course he couldn't tell me what he had done that day. The girls [branch staff] wrote in his diary, so I was able to know what had gone on and what he had been up to. Anyways it gave me the opportunity to get down the town to do my shopping and pick up "*bits and bobs*". It was good for Billy to have a break from me (PG2/6/a).

Older male participants such as Bob also echoed how he felt it was beneficial for his wife Alice to attend a weekly luncheon club facilitated by their local Alzheimer's Society branch. However, as with other male spousal caregivers of both PG1 and PG2, the accessing of group support services for both caregivers and their family member outside of the family home was an uncomfortable experience, but nonetheless undertaken:

> Things began to deteriorate and we joined the Wednesday Lunch Club. I don't know if [name of branch worker] told you? They were wonderful people. There were different people there, with Zimmer frames and walking sticks. Alice liked it there. There were twenty nine women and I was the only man (*laughing*). The carers were wonderful, but I didn't feel comfortable there. But I had to go you see … I wanted to do it for her (PG2/19).

Other participants emphasised their experience of the practical difficulties of their family member accessing services. Patricia, for example, highlighted Nigel's reaction to attending the local Alzheimer's Society day centre:

> He did go to a day centre, three times a week, just up the road from us. Sometimes I would have to take him because he wasn't ready for the bus in the morning. Nigel didn't like that because all of his life he had been in charge and then I was. He didn't like that. People telling him what to do, you could persuade him, but actually telling him, he didn't like that (PG1/10).

Conversely, other spousal caregivers talked about the decision by their family member to not attend day centre services facilitated by the Alzheimer's Society and the consequential effects this had on continuing to care for their husband or wife. Jessie spoke about her incremental loss of her *relationship-self* with her friends during this period and how she began to experience feelings of isolation and depression in carrying out her caring role:

> Eventually I got to know the "*girls*" [Alzheimer's Society branch staff] through one of our neighbours. They suggested that Barry should go to the day centre, to give me a break. At that point I needed it, I'm telling you. But Barry, well he wouldn't have wanted to go, he wasn't anti-social you understand, he just didn't like other people. Other people like him [people with dementia]. … You see I had lost contact with most of my … NO, our friends by then. It would have been good for him to go, and for me. They have one of those "*singing for the brain groups"* now. It would have been nice to go along and sing my heart out … [long pause] because at times I was screaming inside (PG1/18).

In contrast to the experiences of female participants, several male caregivers stated that attending support groups for family members was something they had considered and had initially undertaken, but then they had chosen not to continue. Eric, during our first interview, expressed his wish to maintain his schema of *me-self* in undertaking activities outside of the family and away from his caregiving environment:

> I was offered the chance to go to the carers group, I went once. It wasn't for me. I'd much rather go to my (sic) own club and see my friends. Although I never spoke about Penny and the way she was …well is. A few of them know, but it's just not the place to talk about that. Penny's OK though, our Nicola [name of daughter] is always with her when I go to [name of town] (PG2/3/a).

Many of the participants spoke about their family member who had previously attended day centres, cafés or clubs and reflected that these services had been an entrée to accessing further services. As with other participants George spoke about the beneficial aspects of relinquishing his caregiving role for even short periods of time by saying:

> I've forgotten how long it was before Mabel then started to go to the day centre. Which… I couldn't have done the shopping if she hadn't gone there. Other than that, we just didn't… we didn't go out at all. And then, when she started going to

> the day centre, she also got the chance for, what you call it – respit (sic). One week in seven she used to go for a week's … respite, respite that's it. So I could get my "*act together*". I used to sleep, catch up on my sleep (PG2/13).

Lucy, Sheila and Molly, three women[25] living within the same rural community, collectively spoke about their respective husbands Ralph, Gary and Ben. Their husbands met at the local Alzheimer's Society day centre, had subsequently become friends and had periodically accessed respite care together. Molly reflected on her schemas of *me-self,* as well as her *relationship-self* during this period of her caregiving journey with regard to her carer support group friends by stating:

> We, me, Lucy and Sheila always tried to get the same respite time at [name of residential care home] so our husbands could be there together. It was good for them and good for us too. We could have some "*me time"* with each other, doing things just for us, knowing that they [their respective husbands] were safe (PG1/9).

Other participants spoke about having had or that they were currently receiving care support within the home environment from domiciliary care workers, provided by the local authority. Yet older male caregivers of both PG1 and PG2 expressed that they had initially accessed home support for social reasons for both themselves and their spousal partner, rather than for practical support. For example Brian, who had previously cared for his wife Nell, reflected on this period by saying:

> They came twice a day, once in the morning to get Nell up and dressed …although I always did this because we, me, Nell and the "*lass*" [care worker] could sit and have a natter and a cup of tea. Nell liked that, not just having me. And then they came back in the evening to put her to bed. Sometimes at 6.00 o'clock – can you BELIEVE IT! … Who wants to be in their nightie at 6.00 at night? (PG1/12).

[25] It became apparent that during the course of the single interviews undertaken separately with Lucy, Sheila and Molly (but all on the same day), that they had together previously discussed being involved in my research. They often answered questions from a collective perspective. They defined themselves as "*the carer support girls*" and stated that they "*wanted to give the same support to others that they had received*". The delineation of each of their caregiving journeys outlined that their husbands had been diagnosed at the same time and that Lucy, Sheila and Molly had experienced the final loss of their husbands within 12 months of each other.

This period of negotiating and accessing services, or the decision to not access services within and outside of the family home was reported by participants as lasting for a period of one to three years. However, it was also a period which participants expressed as telescopically merging into a protracted middle period of caregiving, which they defined as being *"the long road"* part of their caregiving journey.

4.1.5 *"The Long Road"*

It is at this point of the dementia caregiving journey where divergent experiences for participants of both groups began to occur. As with previous aspects of their journey, members of PG1 retrospectively reflected on their past caregiving experiences, but emphasised that they envisaged that this period had extended over a five to twelve year phase, prior to the end of life of their cared-for family member. Although only a small minority of participants such as Brian, Sheila, Lucy and Molly, who had received information relating to palliative care or had received external support from health care practitioners within the home environment, differentiated between "*the long road*', palliative care and end of life stages of their journey. In contrast, members of PG2 made reference to two timeframes relating to their current caregiving role. They expressed their perceived continuation of *"the long road"* period of their caregiving journey, as well as an ambiguous and distant horizon.

All participants spoke about *"the long road'* period as experientially being within an often cyclical maelstrom environment of simply getting on and adjusting to the day-to-day physical and psychological aspects of caregiving. They highlighted an epoch of emotional incongruity in relation to aspects of grief and loss, during which they experienced "*good days*" in their attempts to maintain the routine of caregiving and family life. In addition, they also reflected on *"bleak*" and *"dark days"* of deteriorating physical and mental health challenges for not only their family member, but also themselves. In particular, it was a stage of their journey during which difficulties, predominantly appertaining to participants' perceptions of their schemas of self, rapidly fluctuated between their *relationship-self* and *caregiving-self* with regard to not only their cared-for family member, but also other family members and friends.

However, maintaining family life was an important feature during this period. Happy events associated with birthdays and wedding anniversaries were significantly featured as part of participants' individual journeys. Especially as many of the older spousal participants spoke about having celebrated milestone events within their marital relationship. This was also a period during which participants spoke about increasing family involvement and support. Susan for example, in continuing to reflect on her journey, spoke about a party arranged by her son:

> Our [son's name] put on a party for us. It was great, everybody came. Nice food, a couple of sherries (*laughing*). We have some lovely memories of our diamond [sixtieth wedding anniversary]. Well I have, of course… Ronald … he couldn't remember any of it afterwards (PG1/5).

Joyce also highlighted that during this period she had adamantly wished to maintain a sense of normality in caring for both of her parents, Bob and Alice. Particularly with regard to the importance of the celebration of their sixtieth wedding anniversary, but how this did not go according to plan because of further health issues being experienced by her mother:

> We took her on holiday to Tenerife, because we …NO, I made the decision that mum wasn't going to deteriorate and that's when I made the decision that where we went, mum also went. For their sixtieth anniversary we had lots of little parties for her. Whilst we were up in Scotland she was left alone for five minutes and went to look for my dad and fell and fractured her hip again. We paid for an ambulance to bring her back to [name of city]. Of course I went with her; dad came home on the train. What a journey that was (PG1/11).

Ensuring that the person with dementia spent quality time with other members of the immediate or extended family was expressed as being of paramount importance by all of the participants. However, older female caregivers in particular, such as Margaret, Susan, Sheila, Linda and Avril expressed the significance of "*family time*" as being beneficial in achieving respite from their caregiving role, even for short periods.

For example, Avril highlighted the weekly event of Sunday lunch with the family:

> During the week, it was just me and Tom. Some days were good, others not so good; especially in the winter, because the days were long. But Sundays meant that we were all together as a family, the boys and their wives and of course the

> grandchildren. It helped Tom, he loved seeing the children and it also helped me as our daughters-in-law took over the lunch and everything and I could just sit and be with Tom (PG2/1).

However, participants of both groups reported that interactions with other family members would often highlight the progressive cognitive loss of their family member. Spousal participants spoke about the anticipatory challenges relating to the progressive deterioration of the memory of their cared-for husband or wife. For example Roy, who had previously undertaken the role of primary caregiver for his wife Evelyn at home with the support of their daughter, began our interview by indicating the importance of faith for his family. He highlighted the occurrence of a special family event which prompted him to consider the future aspects of his caregiving journey:

> Evelyn had been *"ill"* for a while …but you know your first communion is important and our Chloé [name of granddaughter] looked lovely in her dress. Evelyn really enjoyed the service, but afterwards she asked who the little girl was talking to our Sally [name of daughter]. I didn't have the heart to say that it was our Chloé. It made me think about how Evelyn's memory was … was going and who she may forget next. I just hoped to God that she wouldn't forget our Sally, because I know it would break her heart to *"lose"* her mother like that. They were… very close (PG1/20).

Spousal participants who did not have children such as Patricia, Brian, Alex and Burt, also spoke about the support they received from extended family members during this period. Nevertheless, other participants spoke about having to support other family members whilst carrying out their caregiving role. Alex, who is currently caring for his wife Sheila at home, reflected on the early part of this period as perhaps being the most emotionally challenging stage of his journey so far. Describing how he coped with the psychological and practical aspects of day-to-day life, but more importantly his sense of *relationship-self* and *caregiving-self* with regard to Sheila and his commitment in assisting other family members experiencing ill-health during the continuous long road period:

> Sheila was up and about then, always on the go …always walking about. Wandering here, wandering there, in the house, in the street, in the neighbours', down the coast on her own. I couldn't keep tabs on her. At the time I was running back and forth to [name of town], visiting my mother, she was in her nineties by

> then, but still physically and mentally fit. But, demanding as ever. Anyway, she never liked Sheila. But Sheila is MY wife (*angrily*). Oh, and Sheila's sister had cancer at the time. She's alright now though (PG2/8/b).

Dave also echoed the experiences of other participants in relation to caring during this period. Especially with regard to the physical fitness of their family member, the cared-for-person and the lack of support and information he felt that he had received in assisting him in being able to cope:

> Moira used to get out of the house, don't ask me how, I always locked the door when we were at home. She'd be found walking in the village. She would walk for miles in all weathers. You see she was still physically very fit then. Although people knew her, knew what she was like, what was the matter with her and they often brought her back. Or the police did. They were "*canny"*[26], they knew what was what. But it worried me, her crossing the roads and that. She could have so easily been knocked down, but she always managed to orient herself to going to her mother's house and trying to get the bus down the town. Of course her mother died years ago, but she didn't know that. God it worried me, what could happen. How do you cope with that *Jo?* Nobody tells you how (PG1/6).

Other emotional challenges were also highlighted by participants who spoke about the development of interpersonal difficulties with family members and friends. These challenges particularly related to the denial by family members associated with the diagnosis of dementia being received and the day-to-day aspects of experiential loss in relation to caregiving. Rachael talked about her schema of *relationship self* with regard to her daughter who lives abroad and her perception of denial being expressed by her daughter as to what they were actually experiencing during this protracted period:

> I didn't, well I never have had a good relationship with our Gillian. She was always Ted's girl, a "*daddy's girl*". Some families are like that "*aren't they*?" It's hard to say that, but it's true. Every year she and our [name of grandchild] would come across. We always liked to see the bairn, she's our only grandchild. But seeing Gillian was always a struggle, always a row. …She said that I HAD WANTED to get rid of HER dad, that's why I put him in a home (PG2/2/a).

[26] The word *'canny'* is used here in the local Geordie vernacular, meaning good/kind hearted.

The subsequent loss of relationships with friends was also articulated, but other supportive relationships began to develop during this period, particularly with regard to the involvement of neighbours assisting older male caregivers. Brian gave an example relating to this period which he found to be extremely helpful and which has continued after his wife's death:

> Our nephews and nieces were also good in helping me with Nell, but they had their own lives and their own families. So our neighbours helped out, bringing us food. In fact they still do, even after Nell has gone. Now that is good care! (PG1/12).

Other challenges experienced by participants during this period related to physical ill-health of not only their cared-for family member, but also themselves. Five participants living within the same urban locality, Alan, John, Brian, Burt and Rachael spoke about their spousal partner being admitted to a particular assessment unit within the same specific time frame. Subsequently, each of their spousal partners had developed the hospital infection methicillin-resistant staphylococcus aureus (MRSA).

As with other male participants, John highlighted a recurrent experience where appropriate information was not communicated to him directly:

> May, well she had been up and down health wise for ages, so the GP suggested she went into [name of assessment unit] … And then the doctor said "*I think that she has Parkinson's as well*". Then I find out that she had developed that MRSM. No, that MRSA. I read it in her file, nobody told me straight up and I thought "*how in the hell did that happen …so what's going to happen now?*" (PG1/3).

Alan also emphasised his anger about the care and attention that Ethel, his wife, had received in the same assessment unit during the same period. In wishing to address this and to maintain his schema of *relationship-self* and *caregiving-self*, he had visited Ethel twice a day, especially at meal times:

> …You never know what goes on in these hospital places. That [name of assessment unit], do you know it? Bloody filthy I'm telling you *(emotionally*). One day they [nursing staff] were all sitting in their office at the end as I was coming past … (*tearfully*) and they said that Ethel is going to [name of another unit] the next morning. And then on the Monday they found that she had MRSA, you know that infection… and they transferred her to a cubicle and the person opposite Ethel… I am sure… I am sure… was dead. I had gone into feed Ethel and you

> know what they did? They took all the curtains down and washed the walls and this that and the other… and the floor was flooded with water and I was still feeding her! But the only thing I can say about the staff, some of the nurses were really good, but most of them were poor and that's bad (PG2/2/b).

During this protracted period of their caregiving journey participants, especially older male and female spousal participants, also emphasised issues relating to their own ill-health and the beginning of their anticipated awareness of possible future outcomes regarding their sense of self vis-à-vis their marital partner.

Susan, who was experiencing health problems relating to recurrent and severe asthma during this period, expressed her anticipated concerns by saying:

> I started to think what would have happened if I had died. What would have happened to him if I'd "*popped my clogs first?*" (sic). I know that the family would have looked after him, but it always worried me (PG1/5).

Emergency hospital admissions of spousal participants such as Brian, Brenda, Burt and April highlighted their anticipation of the loss in being unable to continue their caregiving role. They spoke about their associated grief in the possible consideration of relinquishing aspects of their schema of *caregiving-self.* Previously, these four participants had stated that even though they and their spousal partner had accessed services outside of the family home they had not, up until this point of their dementia caregiving journey, sought further support such as respite care.

However, Brian spoke about a crisis event which exemplifies the emotive experience of anticipation by spousal caregivers in being able to continue with their caregiving role:

> Sometimes she was completely "*lost*", metaphorically speaking I mean; didn't know what she was doing and it hurt. I was "*losing her*" … "*I was losing Nell*". It was "*bleak*". I ended up in hospital through her (sic). I sensed that she was getting out of bed to go to the toilet. And she was saying to me "*get out of bed*". It was in the depths of winter and I was sweating and all of a sudden I felt my heart pumping. As it turned out I hadn't had a heart attack, but the doctor told me to slow down. He laid it on the line …I was wrong, doing too much (*reflection*). I then got help twice a week so I could have a *"good* sleep". It wasn't Nell's fault, but I had

> to accept that I needed to take care of me too, because … well it wasn't worth thinking about if … if… I had gone first I mean (PG1/12).

For all of the participants this stage of their caring journey, whether considered retrospectively by members of PG1, or perceived as a current continuation of their caregiving role as highlighted by members of PG2, emphasised intervals of happier events and day-to-day living over many years. Nevertheless, there was an overwhelming acknowledgement and acceptance by participants of the physical and cognitive loss of their cared-for family member. This was the period which participants continually returned to in expressing their awareness of their reality as being a prelude to anticipated losses and future outcomes.

4.1.6 Negotiating Change

As with "*the long road"* period of the caregiving journey, participants also had differing experiences of permanent residential care. They either perceived this period as being a continuation of the "*long road"* period, or for a small minority of members of PG1, as a distinct stage of their caregiving journey. Some members of PG1 and PG2 reflected on their decision to continue to care for their family member at home during this period. However, the choice of the person with dementia moving out of the family home and into a permanent residential care environment was often a continuation of families having previously accessed respite services. For some spousal participants the anticipation of their husband or wife entering residential care was envisaged as relinquishing part of their schema of *relation-self* with their partner. They felt that their schema of *caregiving-self* was also being challenged.

Several spousal participants of both PG1 and PG2 spoke about the decision of the transition of their cared-for family member into residential care as being a continuation of previous and positive experiences of accessing respite services. This decision was often undertaken collectively within the family. For participants who had positive experience of respite, their role of caregiving was visualised and accepted as "*sharing the caring*" with residential care workers. This was particularly highlighted by Sheila in her acknowledgement of her schema of *relationship-self* with not only her carer support group friends, participants, Lucy and Molly, but also her husband Gary by stating:

> We were couples together during all this …my Gary, Ben and Ralph – Lucy and Molly's husbands - all went to the same day centre, same respite places. At the end Gary and Ben were in 'rez' care (sic) [permanent residential care] together, which was nice. In a way "*they were friends too…birds of a feather and all that*". The care staff, well they were great, we did it [caregiving] together (PG1/8).

However, Lucy highlighted her perception of the initial and beneficial aspects relating to her husband Gary entering permanent care, but also an unanticipated outcome:

> We'd thought about it for a while, me and the family and I knew that we would come to this eventually …thinking about "Dad" … Gary going 'in' for good [into residential care]. He'd always liked the home [name of residential home], he'd gone there often enough when we had respite. He knew the staff …they knew him and of course Ralph [Sheila's husband] and Molly's Ben had been in there. And they [staff] were so good with them. But he was only in there for a few months before he died (reflection). …but I was happy that we had done the right thing. It had started to get all too much for me you see …and I know that he would have understood (PG1/7).

However, other female spousal caregivers such as Jane, Maggie and Alma who had expressed their initial wish to *"cope*" with caring for their spousal partners spoke about their eventual consideration of permanent residential care for their respective husbands as being an extremely challenging decision. The selection of which permanent residential care home was explored, but this was often a protracted event. In addition, the anticipation regarding the quality of care being offered by staff was also highlighted as a major concern, particularly for female spousal participants who undertook this route. Avril, who had initially and independently undertaken the role of caregiver for her husband Tom, perceived this part of her journey as a challenge and an imposed surrendering of her schema of *caregiving-self*:

> I can't tell you how many homes the social worker took me round. Some of these places were awful, are awful. The smell …first thing that hits you when you walk in to some of these places and you think to yourself if they [care staff] can't do anything about that, what else are they not doing. [Name of AS care worker] took me to one place… it's like a five-star hotel. You... You go in to the foyer, and it's not a home. You know. I thought, "Well, what...? What's with all this, sort of frontage business?" I mean, I was more interested in who was going to cope with him, like I <u>COPED</u> with him (PG2/1/b).

Both male and female caregivers also spoke about the choice of which permanent residential care home as being difficult to negotiate from both a physical and psychological perspective. Aspects relating to access and transportation, particularly for older spousal caregivers living within rural areas often necessitated ongoing support from other family members. For example, Harry highlighted:

> If it wasn't for our Marie and Ian [name of Marie's husband] taking me in the car I wouldn't be able to get to see Kathy. We have always lived out here in [name of village] … since we were married, but it is difficult to get to [residential care home] in the winter, to the home (PG2/4).

For others, such as Patricia and Marie, permanent residential care for their family member had not initially been considered an option, but occurred as a response to a crisis event relating to ill health being experienced by the caregiver themselves. The loss of their role as primary caregiver manifested as recurrent expressions of guilt with regard to their perceived inability in maintaining their schema of *caregiving-self* and carrying out their caregiving role within the family home. Tearfully Marie said:

> Dad was ill, really poorly and I was just …run down. I needed help … and so mam went into the home. I thought it would just give me a break for a while … but she stayed there. God I feel so guilty. I should have just coped with it (PG2/5/b).

Both male and female participants of PG1 and PG2 who had and continued to be supported by other family members, or had access and were receiving home care services such as Susan, Margaret, Joyce, Maggie, Roy and Eric, had taken the decision of continuing to care for their relative at home. Margaret replicated the opinions of other participants by expressing her personal viewpoint in relation to her schemas of self by saying:

> Joe <u>had</u> to stay at home, with <u>ME</u>. We were always a family you see, me, Joe and the children. We've a big family. Him going in there [permanent residential care] … we'd thought about it and the kids said that they would help more if he stayed at home and they did, they did, they were good …but … no, no "*pet*" [directed to me], it wasn't for him (PG1/4).

In contrast, Bill highlighted that despite the fact that his wife Mary had previously accessed respite services, he hopes that the continuation of care, with the assistance of care staff, will be undertaken by him within the family home. However, he anticipates and accepts that this situation may possibly change in the future:

> Mary had gone into respite a few times, when I was ill, but that was years ago. She didn't like it and I didn't like it either! As I said, she cared for me and so I have and will do the same for her, for as long as I can. I'll be fine (PG2/10/b).

Other spousal participants expressed that initially the decision of their family member entering permanent residential care was due to a crisis event. Nevertheless, they felt that they were still fulfilling their caregiving role and that their schemas of *relationship-self* and *caregiving-self* remained unchallenged. However, during our single interview Patricia further explored her experiences of feelings of guilt in her reflection that during this period she had often felt that the care being provided by the care home staff was negligible:

> I collapsed again and they took me to hospital and I had to have tests for my heart. So I had to be kept in overnight. He had to go into nursing care because physically and mentally… well he couldn't do anything. It was only going to be for a few days, but he ended up staying there …well dying there (*sighing*). Sometimes, I was aware that "*things*" weren't right. Friends, they would always go in to see him [Nigel] and they told me about different "*things"* that they had seen and so when I went up to the home the manager would say "*you've got that face on Patricia*" (*laughing*). It was hard leaving the nursing home, but I went up there every day at different times of the day. In my way of thinking I was still looking after Nigel. I should have been caring for him at home (PG1/10).

Rachael, during our second interview stated that she was pleased that her husband was now *"settled"* in permanent residential care and that his medication had recently been reviewed:

> I felt that from the very beginning of him being in that place [assessment unit] that he had always been over medicated …*"drugged up*". Once he got settled into the new home, the second home [name of the residential care home] and he, we, realised that it was *"his*" home, they [doctor] took him off the drugs and he began to eat better. That had always upset me, thinking that he couldn't enjoy his food, because he always has (PG2/2/b).

Participants of both groups also referred to "*other incidents*" which had occurred whilst their family member was living (members of PG1), or currently living (members of (PG2) in permanent residential care. Incidents which they felt had prompted them to undertake closer involvement in day-to-day activities within the permanent residential care environment.

June, during our third and final interview cited the occurrence of a recent event relating to her husband Sidney, who has been living in a residential care home for nearly a year. She expressed how she simultaneously felt angry and worried about what had happened and her anticipation of the change in their relationship:

> Up until then he had been …sort of smiling and being pleasant, then suddenly, unpleasant. If you … (sic). …apparently he'd "*gone*" for somebody else. This came up at the meeting with the [name of nurse] who told me that Sidney hadn't really hurt anybody, but then said that after that they [the staff] didn't …sort of …want to get too close to him at mealtimes. I was angry about that …not getting close to him at mealtimes what did that mean? That worried me as I thought that he wouldn't get fed properly and so I fed him after that, going up there twice a day. He needed help to eat and that made me sad, I was really *"down*" about it, because I realised that he'd changed in a way and he was starting to "*go*". He was starting to go on to the "*next bit*" [palliative care] (PG2/7/c).

This period of the caregiving journey was expressed by all participants of both groups as being an extremely challenging stage of their journey. Not only in terms of the duration of this period, which many perceived as lasting over several years, but also their continual negotiation of experiential events and personal loss with regard to their family member. They expressed that their schemas of *relationship-self* and *caregiving-self* were often challenged, requiring a continual readjustment of their self-identity.

4.1.7 Differing Perspectives at the End of the Long Road

Again, as with *"the long road"* period of the dementia caregiving journey participants spoke from divergent experiences of caregiving, either within the family home or shared caregiving with permanent residential care staff. Members of PG1 retrospectively reflected on their past caregiving experiences, but reported that the time frame from their family member being relatively physically

fit, to progressing towards requiring palliative and end of life care ranged from a one to three year time-span. However, the majority of older male and female caregivers of PG1 did not differentiate between palliative and end of life care, but perceived it as a continuous end-stage of their caregiving journey. The only exception was Joyce, who had cared for her mother Alice, who highlighted a definitive separation between "*the long road"* period and moving towards the palliative care part of her journey of care:

> Mum was going downhill rapidly – other health issues, not just dementia. I could see that possibly the end was in sight. But dad, well he just plodded on. I think he thought that mum would just remain the same, but I knew that he was worried that he would *"go"* first and his health suffered. Looking back I think that my health also deteriorated. It was so stressful (PG1/11).

The majority of the members of PG2 acknowledged a continuation of their current period of caregiving and their anticipated future horizon of the end of life of their family member, but as with some members of PG1 they did not express a differentiated understanding between the palliative and end of life periods. However, they did acknowledge their anticipated future horizon and the end of their caregiving journey. Nevertheless, during the interview process members of PG1 and three members of PG2 did refer to changes in the health of their family member relating to dietary needs and medication, associating this with the progression of dementia being experienced by their spousal partner or parent. They highlighted '*pin-point'* events which they perceived had led to the deteriorating changes in their family member's health.

Avril, during our third and final interview highlighted a recent event which she perceived as being "*the*" significant, yet unexpected turning point in her husband's progression to a palliative care stage-experience of living with dementia. Her reflective and anticipated feelings related to the relinquishing of her schemas of self and associated with caring for her husband Tom:

> The night staff, you know, in his book, his records, had put things like, "*very restless, refused medication ... had 13 Wheat-a-bix one night*." Which when I found out... I said, "*How could he have...?"* …His weight had gone down to about 7 stone. So, I don't know. I thought "*I'm sitting here in my glory and he's up there"* in [name of home] wasting away. Something was, is going on with him and then he went to bed and just didn't get up. Or they [care staff] didn't get him up.

> He's double-incontinent now. Since then he hasn't been outside. It was sad, but with this I felt that it is starting to come, near to the end. Well, you just prepare yourself don't you …but it's horrible when it does (PG2/1/c).

Conversely, older male members of PG1, such as Brian, George and Roy expressed that they hadn't fully anticipated this part of their caring journey. In exploring this period George reflected back to his wife's initial entry into permanent residential care and how he had blamed himself. However, he had still tried to maintain a balance between his schemas of *relationship-self* and *caregiving-self* with regard to his wife Mabel. Nevertheless, once he reached the palliative care period of his journey he stated that he had been assisted by care staff:

> Like I say …I was 13st and went down to 12st and they [Alzheimer's Society staff] said "*it's too much for yer"* (sic) and I said you're right let's try and get her into a nursing home. That was easier said than done …I couldn't take Mabel, it would have broken my heart, so [name of care worker] took her, but I didn't go to see her for a week. Then when I "*forgave myself*", I used go in four and five times a week to see her and say "*I love you*" and she used to say "*I love you and all*". It took a load off my mind. But then, when she started to go downhill …and mind it was fast. I blamed myself, but the nurses in the home were good. We even talked … you know if I wanted them to "*act"* [Advance Care Planning], but I said I don't want you to force feed her mind, drugging her and that …sticking things up her nose. There's no dignity in THAT. It must hurt *Jo*, does it hurt?
>
> …I didn't want her to be in any pain you see… thankfully she wasn't. As I said, we'd had our money sorted out. So things were in order. I just had to think about …think about the end really (PG1/13).

Other members of PG1 also reflected on the physical deterioration of their spouse or parent. Dave, for example highlighted his wife's appearance and physical fitness during this period, but as with George, he also expressed the recurrent aspect of the lack of information offered to him by care staff:

> What amazed me at the time is that muscularly... movement-wise, Moira was static. Her arms, legs, her head... All the muscular parts ...they just didn't work anymore. And yet her digestive system and all her internal organs appear to be working perfectly. Why did some parts of her body stop

> working, and then other parts operated normally? I just didn't understand. Nobody said why this happens (PG1/6).

Access to information relating to legal matters such as Advance Care Planning (ACP) and Lasting Power of Attorney (LPA) were also highlighted by participants. However, only a small minority of male and female participants had actually acted upon this information. With the majority of the older participants of both participant groups, particularly male caregivers who had not received appropriate information at the very beginning of their care journey, appearing to experience a lack of information relating to the legal, financial and medical aspects of support during this period.

Reflecting back to her distance past, Joyce emphasised her mother's physical deterioration and the subsequent loss she had felt regarding their relationship. However, now post-bereavement Joyce again looked to her future horizon in relation to her schema of *caregiving-self* in relation to her father:

> Mam was so ill. …In and out of hospital. She lost so much weight, so thin. She didn't even look like her at the end. She couldn't speak. Can I say that I was pleased? Is that too awful to admit? …But now I'm thinking that I will have to do it all again with my dad. But unlike with mam we have *"things*" in place …wills, planning and what not for dad. That's helped, sorting out the legal stuff and having information, even with regard to funeral arrangements. There's so much involved and I want to ensure that dad gets what he wants. It doesn't bear thinking about really, what happens next. …Who knows? (PG1/11).

Brian was the only male participant who spoke with regard to support from external care staff during the palliative care period. He reflected on his experience of caring for his wife Nell at home in the last few months of her life, but moved his reflection forward to how, post-bereavement, he now feels with regard to his changing schemas of self:

> She slept… she slept most of the time in the last few months. We had a hospital bed fitted in the smaller bedroom. And it was hard, there's no doubt. But it was just like, in a way, I had a… like a system. Everything was okay, but… they [clinicians] then decided they would stop the feeding through the nose. She wouldn't receive any more liquid. And just give her pain relief as she required. I think it was called the Liverpool… the …Liverpool Care Pathway. She made it for three weeks like that. It was good to have her here at home. … I know she's gone

> and that I am alone now. I rattle around in this big house like a "*pea in a drum*". I should move, but I can't. I feel that she's still here (PG1/12).

However, other participants, especially older male participant members of PG1 such as Alan, Dave, Burt and Roy who having previously been caregivers for their spousal partners within the family home, reflected that they had not been so well informed at either the palliative or end of life periods of their journey. Although George had experienced receiving relevant information relating to ACP during the latter half of his journey of caring for his wife Mabel, he repeated his experience of the lack of initial information at the beginning of his journey being replicated at the very end of his caregiving journey:

> It was only after Mabel passed that someone told me, another carer I think, that I could have brought Mabel home to die. Nobody said anything to me about that. I would have LOVED that … she would have… we would have liked that …but she's "*here*" with me now (PG1/13).

4.1.8 Coming to the End of the Long Road

Four older spousal participants of PG2, namely, Avril, Eric, April and June reflected on their perceived and current view of their schema of *caregiving-self* as being a continuation of their *"long road"* of caring for their husband or wife. Each stating that they had discussed the traditional aspects of end of life, such as funeral wishes and arrangements for their spousal partner with other family members. However, information associated with ACP and legal aspects had, to date, not been sought. Nevertheless, each participant stated that they were aware that these aspects of care would need to be addressed in the near and not too distant future.

Only one participant, Eric, expressed his conscious reasoning as to why he had not undertaken this task:

> If I do this, it's as if I wish caring for Penny would end. But I don't. I don't want to lose her. I don't want *"us"* to end (PG2/3/c).

By expressing this statement Eric highlights the anticipated loss of not only his sense of self in terms of caregiving, but also and perhaps more importantly his perceived relinquishing of his *relationship-self* with his wife. The remaining six participants of PG2, namely Rachael, Harry,

Marie, Alex, Alma and Bill had divergent experiences and perceptions associated with the end of their caregiving journey. Rachael during our third and final interviewed described how her husband Ted had recently died whilst living in permanent residential care. However, she described how she had been able to arrange to have Ted brought back to the family home the night before his funeral:

> It took a lot to arrange, I know that… but the doctor and the carer staff really understood. They knew what he, we'd been through and that I wanted to bring him home…because it's OUR home. I know he'd probably forgotten all about it, but he used to come home, you know, a couple of days a week. And I thought, "*Well, he's not leaving from anywhere else*". So I had him here overnight. And it was… I felt as… I felt as if he'd been home for the last time. The last place he was … was with ME. I was able to do the right thing by him (PG2/2/c).

In contrast to the devastating and unanticipated beginning of her caregiving journey, when her husband had been sectioned under the Mental Health Act and the subsequent challenges they had both experienced over many years, Rachael felt that she was able, at the end of her journey, to reclaim her schema of *relationship-self* vis-à-vis Ted. Rachael acknowledged that this was only achieved with the assistance of care workers and being in receipt of appropriate information and forward planning.

However, Rachael's experience is converse to the perceptual experiences of older male spousal participant members of PG1, such as Alan, Dave, Burt, Roy and particularly George. Each of these men reflected on the lack of information being offered and received at the end of their caregiving journey. Thereby negating the opportunity of personal choice which they felt could have been considered by themselves and other family members.

Harry, as with other members of PG2, spoke about his anticipatory feelings relating to the end of his caring journey. Although his reflections and perceived outcome associated with the end of his wife's life began very early on during the course of our first of three interviews and was continuously repeated during interviews two (b) and three (c):

> Kathy is in the home now. You know that don't you? She has memory problems you see. I miss her [Kathy] being here with me and Lindi [name of dog]. Lindi misses her. Lindi was always Kathy's dog. I bought Lindi for her. But I keep

> thinking about the end, how it will all end… Marie [daughter] helps out, which is great… Kathy was a good wife. … I don't mind if she forgets me (*tearfully*) …I just don't want Lindi to forget Kathy and Kathy to forget Lindi. …Then, then … then I would know that it is the <u>end</u> (PG2/4/a).

At this point during our first interview Lindi [Harry and Kathy's toy poodle], who had quietly been sitting next to me, ran across to Harry as if she intuitively felt that her "*Dad*" needed to be comforted. During the course of our further two interviews Lindi, as if on cue when the topic of conversation became too emotive, would always make her presence felt, either by returning to Harry's side to be with him, or by what can only be described as "*voicing*" her reaction to the emotional atmosphere. These poignant acts of affection would often, momentarily, break the continuity of the interview, but also enabled Harry to further describe that through Lindi, he felt that Kathy was still cognitively "*with*" him in their family home.

Harry's daughter, Marie, during our third and final interview spoke about her mother's deteriorating physical appearance and the ambiguity in her anticipation of what may happen in the not too distant future:

> Mum's health has been up and down. It's been difficult (*sighing*). Obviously, realistically my mother is deteriorating physically. Losing weight, even in the past week, the last ten days, I can see her going down even further. I think that she's starting to decline *Jo*. I don't know where this is going, if it's just a "*glitch"* or is it just ... another progressive decline… or … (*pause*). But this time it seems to have come on very quickly…<u>too</u> quickly (PG/25/c).

Marie continued and as with other participants such as Alex, Alma and Bill, she talked about how she has considered the practicalities of end of life care with regard to ACP, legal matters and funeral arrangements. However, unlike other participants Marie spoke about these aspects in relation to her three schemas of self by stating:

> Caring for my mam has been difficult, but …our relationship was always difficult. Looking back, perhaps there was a mistake. Perhaps I should have never been born. I just feel as though, and *Jo*, I may have said this to you in the past ... that there was a mistake. I realise in my life that my mother has given me more hard times than she has given me hot dinners. The "*drinking*" [reference to alcohol] … it's sad when a father drinks …but when a woman …a mother … (*pause*) …It has

> just always been like that. I think. I feel that they don't see me as a person. I am the "*whipping boy*"; I am good for nothing else, but ... work (*sighing*). But now perhaps the end is near and I have sorted everything out. …I just hope that she *"goes"* before dad …and that's awful to say, but he … well he won't, he just won't cope (PG/2/5/c).

Similarly to Marie, Alex and Bill who are both currently caring for their wives at home echoed the requirement of *"sorting everything out*". Nevertheless, they held differing views with regard to reflecting on their journey and their anticipated future in the continuation of their caregiving role. Alex, during our third and final interview referred to his wish of continuing to care for his wife, Sheila, whilst at the same time struggling with thoughts of post-bereavement and the regaining of his *me-self* sense of self. Something which he felt extremely guilty about:

> Everything is in place [Sheila's will and funeral arrangements]. I don't want to lose her, it is as if I'm wishing it to happen …but …I don't tell people things, like *"the bombshell"* thing I've... I've said to you today *Jo*. Which I've... I've never mentioned it to anybody before you see. Which is …would it be a relief if... if she passes away? And would I then be able to get some of ME back? I've never said that to anybody before. I've thought about it, but I've never said it to anybody. … It's terrible to say that isn't it …to think that (PG/2/8/c).

During our second interview Bill, as with Alex, also spoke about future planning arrangements:

> We had our wills sorted out years ago and I have already talked about the other arrangements … you know end of life *"stuff"*, that's in place. Our funeral plans have been written down, Mary's and mine. She's high church …I am "*low church*" (*smiling*). Faith has always been important to her. It's good to decided what you want at the end; let's face it you don't have the chance at the beginning do you? (PG2/10/b).

However, at the end of our final interview Bill reflected on the entirety of his journey with the repetition of what he had said during our first interview (a), by drawing on the themes of reciprocity and love relating to his schemas of *relationship-self* and *caregiving-self:*

> You know *Jo*, I've told myself that I'd do it all again, right from the start… THE WHOLE LOT …As long as I could get my dodgy knee sorted first … then I would be fine (*laughing*). You see you have to do it… like I said before; she would have

> done it for me. But you have to take care of yourself as well *Jo* …that's really important (PG2/10/c).

Alma was the only member of PG2 who was interviewed only once. This was due to the fact that she had been informed, one day prior to our scheduled interview, by the care staff of the residential home in which her husband Tom was living, that he had developed pneumonia and the end of his life was near. Nevertheless, Alma repeated the same wish as other members of PG2 in the anticipation of their near future horizon of being *"together"* with their spousal partner or parent at the end of the journey:

> We, Tom and I have come this far. It's been a *"long road"*. I only hope that I am there with him at the end and that the priest is also there. He …no <u>WE</u> want that (PG2/9/a).

All of the members of PG2 expressed their wish to be with their family member at the end of their life. This was expressed as a way in which they would be able to negotiate the transition of their schemas of self from their initial perception of having been cared-for, to currently caring for and finally, having provided care for their family member.

4.1.9 Summary of the Topographical Landscape

Within this first thematic overview I have discussed the features of an expansive landscape which collectively reflects the periods and events experienced retrospectively by members of PG1, as well as the retrospective, current and anticipated experiences of members of group PG2. The exploration of their individual landscapes of care highlights participants' generic and divergent experiences of caregiving, beginning with a *"who we were"* period. Then the negotiation of periods associated with pre- and post-diagnosis, as well as the accessing services within and out-with the family home. In addition, participants reflected on a protracted middle period, which appeared to telescopically merge into proceeding and post periods and was defined by participants of both groups as being the "*the long road*" period of their caregiving journey. An exploration of the divergent experiences of participants relating to aspects of the palliative care period is also discussed. Finally, their retrospective and anticipated perspectives of the end of life of their cared-for family relative are also explored.

Embedded within this landscape, participants spoke from three interconnected and fluctuating schemas of self. This emergent concept is associated with their individual *me-self*, their core self and envisaged sense of self. Their *relationship-self*, illustrating their bonded connection in relation to themselves and the cared-for spousal partner or parent, as well as other family members and care workers. Their *caregiving-self* relates to the acquisition and experiential perspective in undertaking their role of familial caregiver.

The environment of this foundational landscape encompassed the practical and emotional support offered or not offered by other family members, as well as peer support from other family caregivers who had or were currently undertaking the same journey. In some cases, although not with all, the provision of assistance and information from care staff during the course of the dementia caregiving journey was also explored. Participants of both groups described how this either helped or did not help them, whilst they simultaneously look back, cope in the present and move forward into the future. Four of the emotional features of the non-linear and conceptual framework of grief and loss, as outlined by Kübler-Ross and Kessler (2005), namely, anger, depression (feelings of isolation) and acceptance were predominantly expressed by participants throughout their day-to-day experiences within the topographical landscape.

Building on the foundational topographical landscape, the next thematic strata is the *communicative landscape*, which continues with the interpretation of the function of communication. I offer the addition of a textual and layered representation of oral (spoken and unspoken), as well as written forms of experiential emotion and expression perceived by participants as either positively accentuating or challenging their interconnected schemas of self.

4.2 The Communicative Landscape

The sub-themes of this second stratum, the *communicative landscape*, are outlined in Figure 8, offering an oral and textual perspective in relation to emotional events of communicative experiences of members of PG1 and PG2. These specific events either challenged or reinforced participants' schemas of self and are presented as feelings of love and loss, empathy and guilt, as well as the importance of acts and expressions of connectedness in relation to the cared-for family member. For some participants the addition of spiritual connectedness with God is also highlighted.

Four of the emotional features of the non-linear and grief loss framework as outlined by Kübler-Ross and Kessler (2005), associated with anger, denial, depression (feelings of isolation) and acceptance, were predominantly expressed by participants throughout their day-to-day experiences of the *topographical landscape*. However, omitted from the foundational topographical landscape were the remaining '*grief tools'* which relate to bargaining. This was expressed by only one participant and is explored within this second stratum of the landscape of care.

4.2.1 Love and Loss

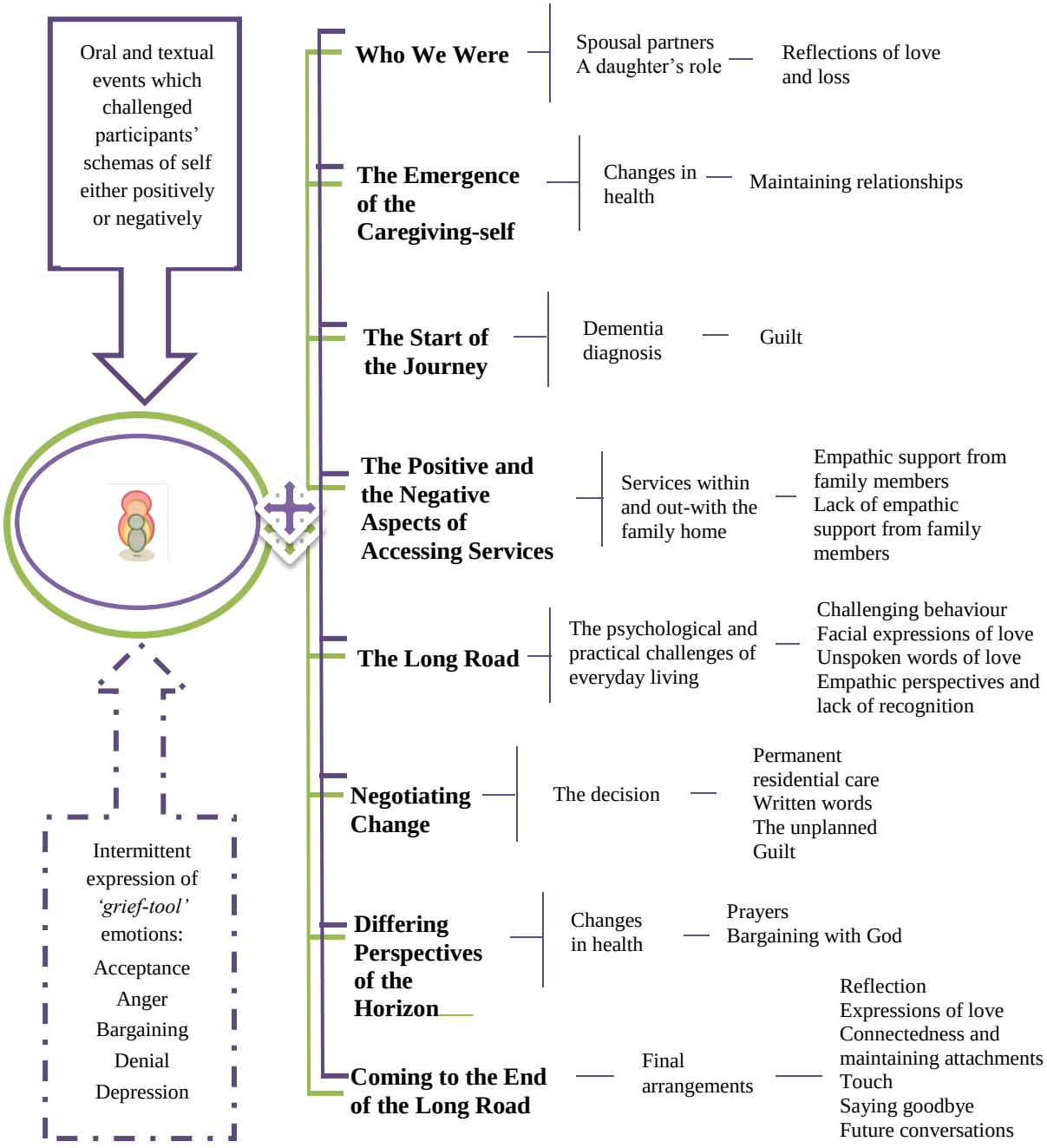
As with the foundational stratum, participants reflected on specific examples of expressions of reciprocal love between themselves and their cared-for family members during various periods of their caregiving journey. For example, members of both participant groups, such as Jane, Margaret, Joyce, Bob, April and Bill spoke about direct expressions of love which they felt accentuated or challenged their perceived *relationship-self* with their partner or parent. Jane highlighted the loss of expressions of love she had previously received from her husband and how during the intense middle part, "*the long road'* period of her journey, this had challenged her perception of her schema of *relationship-self*:

> Before, you know …the dementia; he always used to leave little presents for me or daft notes on the fridge. Then that stopped. I missed them. Not the presents or the words you understand, but the thought. It made me think that perhaps he had stopped loving me? That's silly I know, but … it's silly thinking like that. It was the dementia. I KNOW THAT NOW (PG1/1).

In contrast, Susan reflected on how her continuous expressions of love to her husband as a way in which she perceived she was able to maintain her relationship with him, particularly after experiencing challenging situations whilst caring for him at home:

> Men don't say *"I love you"* and all that do they? Well men of Ronald's age don't! Well he never had (*laughing*). But I would tell him often. When I had lost my temper when we were first married - I told you I was a *"little devil"* - I'd fly off the handle for no reason. Then when he was, no when the *"dementias"* made him difficult and after he'd calmed down, I would tell him over and over again "*I love you, I love you"* and we were alright again. Until the next time (PG1/5).

Figure 8 Themes within the Communicative Landscape



Susan was the only participant member of both groups who spoke about experiencing physically aggressive behaviour by their family member within the family home. She expressed that this event challenged both her *relationship self* and *caregiving-self*:

> One day, Roland chased our Hazel [name of daughter] out of the kitchen. He was going to hit her with … with one of those big jars of coffee. I had to stop him. I shouted at him and he just shrugged his shoulders and went upstairs, cool as you like …as if nothing had happened! I could see that our Hazel was frightened, but she just hugged me and said *"mam, it isn't dad, it's the dementia".* That really shook me …that Roland was going to lift his hand to our daughter, he'd never smacked her before … when she was a child. He'd never really told her off. That was always my *'job'*. Then an hour later, when Hazel had gone to pick up the grand-bairns from school Roland asked "*is Hazel coming today?"* and I knew that he loved her, he loved us really. In his own way and where he *"was"*. We just had to care for him as best we could (PG1/5).

Other challenges to participants' schema of *caregiving-self* related to the initial denial by other family members of the cared-for-person actually having dementia. This was specifically explored again in the second interview with Rachael, during which she highlighted a repetitive conversation with her daughter:

> Last time our Gillian was here she said that her *'dad'* didn't have dementia and that, like I said before *Jo*, that I had *"just wanted to get him out of the house*". He was sectioned for God sake! That really hurt. How could MY daughter, a member of MY own family say that! I LOVE Ted. But she's just in "*denial"* about the whole thing, won't accept it. It was the same when Ted had that …MRSA in the unit. She was just the same crying and going on …always a row (PG2/5/b).

However, the majority of the participants spoke about conversations that intensified family support. In contrast to Rachael, Joyce reflected on the end of life period and the final loss of her mother Alice, in emphasising her schema of self by stating:

> Each and every day, from when I was a little girl I always told mum that *"I love you mum",* because I did, I do. We just have, sorry, had that sort of relationship. Very '*touchy feely'* and she would always kiss me and would say *"I love you too Joyce".* This happened right up until she died, although by then she couldn't speak and so just made a gesture. But I knew what she meant. You do don't you? In the

> hospital she touched my hand and I knew …I knew that I was still her *"little girl"*. Dad was there, which was good.

Bob, Joyce's father, also echoed his accepted perception of having to say *"goodbye*" to his wife Alice:

> It had to come, the end, when Alice was going, was leaving me and the children. I knew that. She was so ill, but the nurses were amazed, because she said *"I love you Bob"* and held my hand (PG1/19).

Four members of PG1, Susan, Dave, Linda and Brenda reflected on the fact that they had not physically been "*with*" their spousal partner at the end of their life. Yet they offered an accepted interpretation of this event as being the final act of love offered to them by their respective partners. Susan for example, talked about her husband, Ronald, entering a hospice as he had also been diagnosed with lung cancer and how the family had told her that it was "*near the end*":

> … Our Hazel had said that it was "*near the end*" for dad. It was the cancer that got him in the end you know. He used to say "*you*", (pointing to herself) "*go home, go home!",* because I used to go in at 11.00 o'clock and stay until 7.30 p.m. to feed him. I used to go in everyday to help the nurses …mind they had him lovely (*smiling*). He was taken in on the Wednesday a week before he died. On the following Thursday, funnily enough, as we were coming away and he goes like this to me [waving] (*emotionally*) and I waved back and …*hum*, on the Friday we didn't get in, I forget what had happened, but Hazel said "*we won't go in tonight, we'll give him a break*" and ...*hum, hum* (*very tearful*) and he just went and died… I think it was his way of not having me there, not seeing him go. He was thinking of ME. I have heard that they [people with dementia] do that, go when you aren't there (PG/1/5).

Expressions of love communicated through body language were also highlighted by members of PG2 who were currently caring for their family members with an advanced-stage-experience of dementia, either within a residential care environment or within the family home. April and Bill spoke about their interpretation of facial expressions by their spousal partners, which they recognised as an integral aspect in the preservation of their *relationship-self* whilst carrying out their caregiving role for their individual partners.

April, with a beaming smile on her face said in our third and final interview:

> The one thing about Billy, the one thing which I am really thankful for is that he has never lost his smile. Every time I walk into the room I get the same smile I got when I first met him *(giggling).* It's lovely. After all these years he still loves me … oh and the bairns of course (PG2/6/c).

Bill in contrast spoke about the development of facial expressions by his wife Mary that enables him to interpret her emotions and assists him in his caregiving role:

> When Mary was … well, put in bed, God that sounds awful doesn't it? When she couldn't get around by herself … eight years ago now … I was helping her drink a cup of tea one day. But I went and spilled the tea all over the bedsheets. So I lost my temper. I had always been bad tempered you see…then she gave me <u>that</u> look (*pulling his face*) … and I could just hear what she always used to say to me "*lad, you need to calm yourself down*". She was right. I still had to clean up the mess of course. There was no point in getting annoyed about it. I have never seen that look again from her. I have learnt that from her. She was always good at caring and now I am caring for her and I have to do it right. I love how she blinks and smiles at me …well not just me everyone. It lets me know that she feels safe and is happy and that's the main thing (PG2/10/b).

However, one participant Marie highlighted a recurrent and challenging theme in relation to love and caring for her mother, Kathy. During our second interview Marie produced a bundle of letters neatly tied together with a thick red ribbon[27], which her mother had sent when she had initially entered permanent residential care. Marie felt that the contents of some of these letters questioned her self-identity, particularly her *relationship-self* to not only her mother, but also her father:

> Mam had to go into care you see, because dad was ill. I didn't want that to happen, but then I started to receive these letters from her. She was still able to write, but her writing wasn't as neat. She was a lovely writer. But she said things like this: "*YOU (meaning me), put <u>ME</u> in here so you could be with your father. I hope that bugger falls down the stairs and breaks his neck. And you, what sort of daughter*

[27] Marie offered me the opportunity to read all of the letters written to her by her mother. However, I felt that this was not an appropriate method of data collection. Nevertheless, Marie then asked if she could read excerpts of the letters to me during the interview.

> *are you? If I didn't know any better I think that you aren't my daughter and just want to keep him (dad) for yourself"* (PG2/5/b).

Marie continued by saying,

> *Jo,* I feel so guilty. Looking back perhaps I should have tried harder to care for my mam at home, at least for a little longer. I love her. Dad loves her. She never wrote to him and he doesn't know about these letters. It would break his heart. But I feel that I am always protecting him, but he isn't in a position to protect ME. Sorry, I shouldn't think like that (PG2/5/b).

In expressing this Marie felt that she was not receiving reciprocal support from her father which is normally associated with the parent and child relationship. Yet clearly for Marie the bonds of love and attachment to both of her parents remained intact.

4.2.2 Guilt

Emotional expressions of guilt were predominantly highlighted by members of PG1, who post-bereavement, were currently in a position to retrospectively look back over their entire caregiving journey. However, as with Marie, expressions of guilt primarily related to the period of participants' consideration of their family member entering permanent residential care, particularly intensified if initially undertaken as a planned period of respite, but which subsequently changed to a permanent arrangement. For example, Patricia spoke about her feelings of guilt and her perceived challenge of her schemas of *relationship-self* and *caregiving-self* with regard to her husband Nigel:

> He initially went in for two weeks respite because I was ill, but then it became permanent. I didn't want that … but I was exhausted mentally, emotionally, physically, spiritually - everything. This was MY husband who had always protected ME *(emphasis).* He had always been my "*fortress, my rock, my country*" and here he was - helpless. He didn't know. So, you just have to get on with it. But I put him in there …that's me feeling guilty. …The care staff, especially the manager told me over and over *"it isn't your fault. We are helping you to care for Nigel".* I know that they meant well, but I didn't want that … him being in there because of ME. …Each time I saw him, up there [within the care home] I would

> hug him so tight and he would touch my face. I hated saying *"goodbye"* and coming home, coming home to OUR HOME (PG1/10).

Only one participant, Alan, reflected on his entire caregiving journey as being continuously and overwhelming filled with the emotional expression of guilt. This related to a misunderstanding of communication at the very beginning of his journey and now, post-bereavement, his perception of not having successfully fulfilled his schemas of *relationship-self* and *caregiving-self* towards his wife Ethel:

> …And then the Dr. [name] sent us to see this gentleman (*consultant*) …I missed the appointment by one day. My fault - totally my fault, it was last thing that I wanted to do for her, for Ethel, missing her appointment. Well he wouldn't see us, I said to his secretary *"I apologise, but can [name of consultant] see us on another day?"* And she said "*possibly*". But he ignored us, wouldn't have anything to do with us. I had to go back to our doctor. It was like starting all over again. Little did I know that because of ME, and I totally BLAME MYSELF here …it would take several years for Ethel to get a proper diagnosis. Forgetting the appointment was bloody stupid of me. You know I think it stopped Ethel getting other things, like day-care. If I could do it all over again …and I would …but I can't (*sighing*), I would do it so differently … but I didn't do IT right. I didn't do it right [caring] (PG1/2).

In his reflection of his caregiving journey Alan emphasised not only his sense of guilt, but also his empathically perceived view that having inadvertently missed this initial appointment, this had drastic repercussions for Ethel, his wife, in being unable to access additional services.

4.2.3. Empathy

Other spousal participants of PG1 and PG2 also interpreted and spoke about their empathic positioning in relation to their family member, which they had undertaken, but nevertheless found to be challenging to their schemas of self. Examples were predominantly reflected as occurring during the *"long road*" and latter periods of their caregiving journey, during which the development as to the lack of recognition of the caregiver by their cared-for family member had begun to emerge. Participants' schemas of self, of who they perceived themselves as being, began to fluctuate, often moment-by-moment within their daily activities.

Jessie, having cared independently for her husband Barry at home for several years, highlighted recurrent events which not only accentuated her perception of the progression of her husband's dementia, but also challenged her sense of self with regards to her relation to him:

> It must have been difficult for him, but I missed being with and talking with my friends. I lost my friends. I had to accept that I was just isolated. It was just me and him. Then as he got progressively worse he just didn't recognise me as being *'me'*. As I said, the worst of it was the shouting going on, especially when I tried to bathe him. You see he wouldn't even let me get help for that …turned the girls (domiciliary care staff) away. And so each time I tried to put him in the shower or bath him he would shout *"get off me you dirty old woman, get off me. And where's 'my' Jess?"* and I would say *"it's me, it's me"* and he would say …well I won't tell you what he said, but I knew, even then, that I had *"lost my Barry"*. That went on for years …him living with …who he thought was a "*dirty old woman"* (PG1/18).

She then continued by adding her perceived feelings of the ambiguity and the challenges to her experiential schemas of self by stating:

> Although sometimes he would ask me *"do you know 'wor' Jessie? ...I love 'my' Jessie".* I took comfort in him saying that. Well that was all that there was left really (*sighing*). But to him I suppose I was still with him, somewhere. God knows where though (PG1/18).

Alex during our third and final interview spoke about his neighbour and how he felt that she had empathically assisted him in caring for his wife, Sheila. Nevertheless, his perception of self changed:

> A few years ago we were in the living room and Sheila started screaming. I didn't know what was wrong with her and I got hold of her arm and she screamed even more. Our neighbour, Mavis, came in because she had heard the noise and asked Sheila what was wrong. Mavis knew how to help; she had been through it all before [dementia care] with her husband you see. Sheila shouted *"get that man out of <u>OUR</u> house – where's Alex?"* Mavis said "*that's a lovely picture of you and Alex"* pointing to a photograph taken when we were on holiday. That calmed Sheila down. Then Sheila kissed the photo (*pausing*). …From that day Sheila seems to accept me being in the house, but now she always talks to the *"Alex"* in the photo. Funnily enough she talks to Mavis and the care girls directly, but not to

> me. She listens though. That's alright …I understand …I am just her carer now (*tearfully*) (PG2/8c).

The received expression of empathy from other family members relating to the acknowledgment of the participant's caregiving role was highlighted by each participant, with the exception of Rachael and her conversations with her daughter. However, there was one example given by April, who highlighted the collective decision made by her family associated with her husband Billy and herself accessing other services outside of the family home:

> As a '*family*', we talked about it … me, Billy and the kids agreed. They all said *"you need a break mam"*. I even spoke to "*our*" Stuart. Well I said *"what do you think about dad going to the club on a Tuesday?"* and he said *"do whatever you need mam, look after yourself"*. You see … I talk to "*our*" Stuart every day … even though he is no longer with us. He was murdered seven years ago you know …but he always says the right thing and that helps (PG2/6/a).

At this point of our conversation, undertaken on an airless summer day, there was a single gust of wind which momentarily blew the lace curtains into the room, touching April on her shoulders and then receding. Pointing to a photograph of her family, April offered a subjective and spiritual interpretation by saying:

> That's our Stuart! Like I say he is always here to help. He's always with me and Billy (PG2/6a).

It was apparent that April took great comfort in being able to *'connect'* with all of her family members and to include them in family decisions.

4.2.4 Connectedness

The continuation of attachment and metaphorically being *"with"* the person with dementia was attained by the use of photographs and talking to photographs of their family member by participants of PG1. They utilised and interpreted photographs as being a conduit of sustaining a non-physical and spiritual *"connectedness"* with their spousal partner or parent post-bereavement. John echoed the central and beneficial tenet expressed by participants of talking to photographs of their family member by saying:

> It helps; it's as if they are still *"here"*. It is as if they haven't gone. It's like that *"in the next room poem"* – you know that lovely one they read at funerals[28] (PG1/3).

Five other members of PG1, Alan, Susan, Molly, Patricia and George also utilised photographs of their spousal partner within particular areas of their home. These photographs were surrounded by candles and ornaments creating a personalised shrine, although not of a formal religious nature.

Patricia spoke about the comfort she received in having this spiritual connectedness with her husband and how this had become a daily ritual for her:

> … You see, even now Nigel was ….is <u>still</u> my husband (emphasis). I tell him everything. I talk to his picture every morning and night. Like I had a lady coming from the university today, it helps to tell him things. You know I had a bad day the other day and I was telling him, and I am sure his eyes filled with tears. I know that it's just a photograph. I know physically that it is impossible. It's silly, but it still helps (PG1/10).

Patricia explained that she felt that these conversations kept Nigel close to her, enabling her to feel his presence. Although she quickly assured me that they only took place in their bedroom, so "*I wasn't to worry, he wasn't able to hear us*".

Members of PG2 whose family member is currently living in residential care also spoke about using photographs as a way in which they maintained a day-to-day connection with their husband or wife. Harry, for example stated that he and Lindi [name of family dog] spoke to his and his wife's wedding photograph. Especially on days when he is unable to visit his wife within the care home:

> Sometimes it is because I am not too well, or in the winter when it has been snowing heavily. I am not good on my feet you see. But I know that Kathy understands. We tell '*mum*' *"sorry pet, but we can't get in to see you today, but our Marie will be coming this afternoon"* (PG2/4/c).

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28 I believe John was referring to the poem "*Death Is Nothing At All*" by Henry Scott-Holland.

Reflecting on conversational aspects of their caregiving journey, all of the spousal members of PG1 and PG2 referred back to distant horizons with regards to their *relationship-self* and the commitment of "*in sickness and in health*" they had made to their marital partner. Roy, reflecting on faith in particular as being extremely important, talked further about how his religious belief and support from other church members was of great *"comfort"* and *"support*" to him, especially whilst caring for his wife Evelyn:

> It brings me … it brought me great comfort. You know, the old Father still comes to visit me at home sometimes, even though Evelyn is now gone. And I often tell him, "*Father, Evelyn and I told each other [when we got married] that it was all about in sickness and health",* the good, as well as the bad times. He always says *"you were given lots of strength [from God] in being able to support you in caring for Evelyn. It was a difficult time for you and for the family".* And you know he was right …but I wouldn't change a thing (PG1/20).

Bill in contrast spoke about receiving spiritual comfort within the family home by saying:

> Each night I read Mary her prayers, it's our *"special time"* together. Going to church was always important to her. I lapsed years ago mind you (*laughing*), but I always add a little pray for me at the end, asking for [his] help in being able to continue to care for Mary (PG2/10/c).

Spiritual '*conversations*' with God were also highlighted as an integral part of their day-to-day activities by members of PG1 and PG2. Although unlike for Roy, these acts of talking with God were not perceived as being fundamentally religious acts, but as with Bill (PG2/10c), related to their schemas of *relationship-self* and *caregiving-self* in being able to continue aspects of connectedness with their cared-for family member.

Nevertheless, one participant, Alex, in our third and final interview reflected on his perceived situation as continuing on *"the long road"* of his caregiving journey by saying:

> She's [Sheila] not going into one of those places [permanent residential care], over my dead body. … I've already said to Him [pointing upwards], "*I'll keep her here, without help as long as it takes, but please ...take her first …not me"* (PG2/8/c).

With this comment Alex was the only participant of PG1 and PG2 who displayed an example of the dialogical '*grief-tool'* of '*bargaining*' between himself and God. Nevertheless, other participants of PG2 spoke openly in acknowledging their anticipated concerns in relation to the possibility of dying before their family member and undertaking conciliatory conversations with God.

For members of PG1 there were also conversations undertaken with God. For example, Patricia stated that her *"goodbye"* to her husband Nigel was physical in nature, yet her conversations around the time of Nigel's death and beyond, were with God:

> He [Nigel] had always recognised me as his wife, but in the latter stages he, I think …recognised me as someone *'special'*, someone that he could trust. You see that night when I wasn't there [in the care home] he had fallen and split his head open. After that he never opened his eyes again. When I went into the hospital, he was taken straight there on the Tuesday; I held his hand all night. And he died peacefully on the Wednesday. But I felt that God wasn't there. I sobbed and sobbed, which surprised me because I think that I had been grieving for my *'lost'* husband for such a long time. But you would think when death actually comes, that you have done all the crying and soul-searching, but you haven't. You haven't. And then I just thought "*why did this happen to me?*" and I got very angry with God. I asked him over and over… "*Why? Why? WHY*?" Months later I was still angry and I said to one of our ministers "*so where was HE* [God] *in that scene then?*" and the minister's answer stopped me in my tracks because he said "*He was there but you forgot, because as soon as you took Nigel's hand he was calm that is when He* [God] *came through for you*". That absolutely amazed me that I hadn't seen Him in my anger, but somehow I could see Him now. I felt that after months of being angry my faith was restored …somewhat (PG1/10).

Faith and ritual played an important part for participants, especially for those who had experienced the planning of funeral arrangements. During our first and only interview Alma spoke about having recently undertaking the planning of her husband's funeral:

> We [the family] have talked about things, what to have… hymns and the like. No flowers… Tom had a couple of charities that he always gave to and I want to give something to the branch [Alzheimer's Society], they've been so helpful. I spoke to Tom the other day and told him… "*We are going to have your favourite hymns played; you'd like that won't you?"* The Father [priest] has been so supportive and

> is coming to give the last rites, which will help. In a way I have already said my *"goodbyes*". My only concern is that I know that it is near the end now. I only hope I am there with him. It would be awful to have come this far and not be there (PG2/9/a).

As Alma highlighted, the most important conversation for participants during their entire dementia caregiving journey was being able to be with and to physically say *"goodbye"* to their family member. For participants of PG1 who had experienced the final loss of their spousal partner, or as with Joyce her parent, this had brought to an end many years of caregiving. For participants such as Susan who were not physically present at the end of their spousal partner's life, this was perceived and interpreted by participants as being the final "*act of love"* by their spousal partner in emotionally shielding them from this event. With regard to members of PG2 who were anticipating the end of life of their family member as being positioned within a distant horizon, there was overwhelming hope that they could be with their relative and would be able to say their final "*goodbye*". However, they acknowledged that this would bring an end to their journey, their physical connectedness with their family member and a relinquishing of aspects of their own self-identity.

4.2.5 Reflecting on Past and Anticipating Possible Future Conversations

At the end of the single interview with members of PG1 and the third and final interview with members of PG2, participants were asked to offer a retrospective overview of their journey, which incorporated a review of their caregiving role and what they perceived their future may bring. Joyce echoed the thoughts of other PG1 participants relating to conversations which she wished she had been able to have during her caregiving journey:

> Perhaps if someone like Social Services or the doctor had told me "*this is how you do it' [caring]… this is what you do when…"* I think that it would have been so much easier, but perhaps they can't because no two people are the same are they? You just have to find your own way through it. But once we got [names of Alzheimer's Society workers] on-board (*laughing*), things began to fall into place, practical services and that… and then at the end… nothing. I mean just having

> someone to talk it through… the whole thing. But this is good *Jo*… just talking about it, I mean with someone who understands (PG1/11).

Ongoing support and conversations with Alzheimer's Society staff were highlighted by all of the participants of both groups, including Alan and other older male caregivers, as being extremely beneficial. Although older male and female participants acknowledged that the information offered towards the final periods of their journey in terms of ACP or other legal aspects relating to end of life were not necessarily acted upon. However, at the end of our third and final interview Marie, as with other members of PG2, echoed Joyce's views by expressing her thoughts regarding the communication of appropriate information and support post-bereavement:

> I think that we need to do a lot more for people with dementia and I think that the government should do a lot more for the family and those who are carers. It is all well and good that we have voluntary organisations, but they can't do everything *(angrily*). And what they do is being cut back. The government needs to re-evaluate all of that, definitely. There needs to be more information, people to talk to…so you can say "*this is what happened; this is how I coped and so where do I go from here?"* After it all… what then… what happens then? It's not just a '*normal*' thing, a normal death I mean… I keep saying to myself that "*it's been going on for years… mam leaving… leaving us… leaving me*" (PG2/5/c).

In her final reflection Marie's sense of self is challenged in considering her retrospective and prospective experience of caring for her mother.

Jessie was the only participant who spoke about her wishes for conversations in the future which were of an extremely personal nature:

> I am worried about my own memory you see …the girls at the branch [Alzheimer's Society] have been helpful and suggested that I see the doctor, but I think it is just that I feel all alone now. I did it [caring] for so long you see. I was with Barry for so long. It would be nice to meet someone …not to get married again you understand, NO NOT THAT! …just to have a companion …to get out …for a run down the coast maybe. I could just be me. But I don't think our children would like that (PG1/18).

With this comment Jessie expressed a re-adjustment of her schemas of self, not only relating to her concerns about her own memory, but also with regard to who she perceived herself as being in the future. Nevertheless, she felt isolated and that her schematic sense of self was still rooted within her caregiving relationship with her husband.

4.2.6 Summary of the Communicative Landscape

This second landscape, the *communicative landscape*, builds on the expansive topographical terrain and the emotive experiences of change, grief and loss. In contrast to the day-to-day conversations within the *topographical landscape*, this second stratified layer presents intensive aspects of thematic communication which participants felt accentuated or challenged their perceived schemas of self during the middle to latter periods of their journey. Emotive conversational exchanges were highlighted by participants as being verbal (the said and the unsaid), textual (in written format), or tactile (with reference to facial expressions and touch). Yet the dominant actual and perceived experiences of emotion and feelings related to *love*, *empathy* and *connectedness*, which participants found to be not only comforting, but also a reinforcement of their schemas of self.

Nevertheless, the exploration of this communicative layer of their landscape of care also highlighted those conversations which appeared to be ambiguous and at times challenging to participants' self schemas and the feelings of *guilt*. In addition, participants reiterated their communicative experiences which they had undertaken, or which they wished they could have been able to undertake with clinicians, care workers and others offering practical and emotional support. These conversations specifically related to the receiving or not receiving appropriate information at the beginning and also at the end of their journeys, which participants felt to be relevant to their caregiving role. Also highlighted were dialogues with God, as well as internalised, poignant and mindful '*conversations*' undertaken within their perceived schemas of self.

4.3 Orientation of Self and Wellbeing within the Landscape

Building on the foundational caregiving terrain which explored the expansive psychological day-to-day events and periods of the *topographical landscape* and the smaller dialogical overlay of the oral and textual perspectives of specific and emotive conversations outlined in the *communicative*

landscape, the third stratified layer offers the thematic orientation of self and wellbeing within the landscape of care and is depicted in Figure 9. This final stratum explores participants' perception and transition of self associated with strategies and routines undertaken, although not by all participants, in maintaining their sense of self and wellbeing during the latter periods of their caregiving journey. Participants undertook varying approaches in navigating and re-orientating themselves in response to their experiential losses, both physically and cognitively, in relation to their cared-for family member and themselves.

In the exploration of the overall lived-experience of caregivers and their contextual perception of their schemas of self within the landscape of care, they spontaneously vacillated between past, present and future aspects of their journey. The majority of the members of both groups spoke about various strategies and routines which they had adopted during specific periods of their journey or, as in the case of members of PG2, were continuing to undertake. These strategies included physically "*getting out and about*" and enjoying independent activities, as well as undertaking activities with others such as family members, friends and other caregivers. In addition, those who did not undertake physical pursuits outside of their previous or current caregiving role, spoke about their wish to maintain and to reflect on their ties of attachment with their family member. However, some participants highlighted more mindful activities relating to documenting their emotions and feelings, which they felt enabled them to be present within the moment.

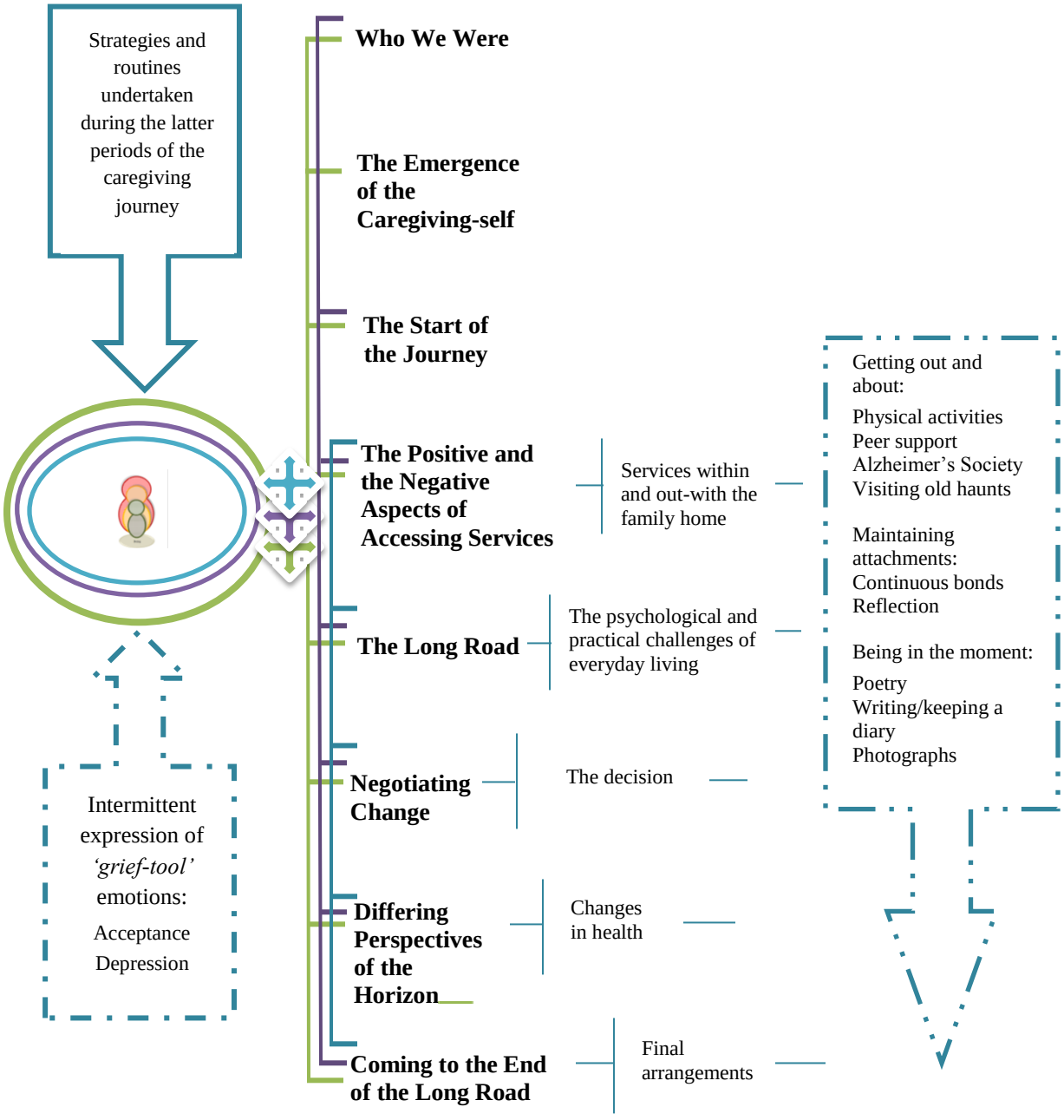
4.3.1. Getting Out and About

The acknowledgment by participants of their need for what they referred to as *"me time"*, was extremely important. Participants from both groups spoke about physical activities they had or were currently undertaking. Particularly, this related to male participants, who spoke about enjoying physical pursuits independently of others and out-with their caregiving role. For example, Eric expressed his awareness regarding the importance of having *"me time*" away from his caregiving role by stating:

> I have been going to the pool whenever there's someone in the house [a family member or local authority care worker] staying with Penny. I mean, I've... I've

gone up and had an hour in the pool, so I quite enjoy it. And I need the exercise. I have a really busy diary. I just need to "*chill out*" and do my own thing occasionally. I need time for ME (PG2/3/b).

Figure 9 Themes within the Orientation of Self and Wellbeing within the Landscape



However, during our second interview Alex spoke about his anticipation in relation to the future and also what he was currently doing to re-orientate himself and his attempts to regain his sense of *"me-self"* within his continuing journey of caring for his wife Sheila:

> Now all I can do is just go out when I can, when the girls (domiciliary care workers) are here and walk along the sea front. I walk and walk …sometimes for hours. Sometimes …I just don't want to come back. But then I think about the future and how I'll feel when she's gone. That always brings me back to her (PG2/8/b).

In contrast, female participants of both groups such as Jane, Susan, Lucy, Sheila, Molly, Patricia and Avril, with the exception of the two caregiving daughters Joyce and Marie, highlighted the beneficial aspects of continuing to be part of peer support groups and activities for family carers facilitated by their local branch of the Alzheimer's Society. Avril stated:

> Going to the meetings and "*getting out and about*" means that we can talk about things with the other carers; most of them are women you know! We can talk about things, which we don't want to tell the family about. We can share things, because we are all in the "*same boat"*. We can just be ourselves (PG2/1/c).

Older female caregivers of both groups such as Margaret, Linda, Jessie and June, also spoke about "*me time*", but related this to spending time with their family members and other caregivers. Linda stated:

> After Henry died I just didn't know what to do with myself, but I started going back to the branch (Alzheimer's Society) and I am involved with the fundraising. It means that we, our family, can do things together – it helps me and it's a way of remembering Henry. He'd like that (*smiling*) (PG1/14).

Maintaining the *relationship-self*, the close bonds of attachment between the caregiver, the cared-for-person and other family members was also a prominent feature for participants. Brenda echoed the experiences of other caregivers by reflecting on a routine she had previously undertook with her husband by stating:

> We often went out with our nieces. …When he was still at home, before going in [permanent residential care], I used to take him to our "*old haunts"*, where we used

> to go during our courting days. That used to help … getting Don back, if only for a short time. We'd go to down to the cliffs and just sit with a flask of coffee. …Then one day he just said "*the first day sailing out of the river was the happiest day of his life"*. …And there was me thinking that it was the day he met ME (*laughing*). But it didn't matter, he was *"there"* somewhere, way back and I was there thinking of the past, the present and the future, but we were still "*there together"* (PG1/15).

As with Brenda, spousal participants talked about various strategies which they undertook, especially during "*the long road*" period of care, which they felt not only helped to maintain their own sense of wellbeing, but was also a way in which they could enjoy time with their spouse. Only two male participants, Alan and Bob, spoke about their enjoyment of undertaking joint activities with their spousal partners outside of the family home during the latter periods of their caregiving journey. However, Alan highlighted that post-bereavement his routine of continuing to visit a local café is an emotional experience for him:

> When Ethel was at the hairdressers … she loved going (*smiling*), I think it made her feel better – that made me feel better as well! And the "*girls"* (salon staff) were always good with her; I would go to the café next door for an hour or two and have something to eat. I still go once a month to see them and have my dinner. …Sometimes I think that she is still getting her hair done. Then I realise she isn't. And that's …. But I don't want to stop going. It's as though she is still here …and we are doing what we always did (*tearfully*) (PG1/2).

However, there were gender differentiated views offered by male and female participants of both groups associated with the seeking and the undertaking of activities for themselves beyond their caregiving roles. The majority of male participants sought individual activities, or pursuits which did not involve other caregivers. In contrast, female participants took part in peer support groups and other caregiving activities with the cared-for-person and other family members. This was often perceived by participants as a strategy of maintaining their ties of attachment with their spousal partner.

4.3.2 Maintaining the Ties of Attachment

Conversely, two male members of PG1 spoke about their perceived relinquishing of ties with their spousal partner post-bereavement in terms of their schemas of self. George emphasised this at the

very beginning of our interview relating to the "*who we were*" period and then rapidly moved forward to his post-bereavement present in his reflection by stating:

> Looking back at it all now, my journey, I wasn't as good at doing the cooking and cleaning and that, like her. But I suppose I will never be the same again. Well, you don't ever go back to who you were …you change don't you? Do you? But now she is gone (*emotionally*) and I am left, it would be nice to go back to being "*me*" again (PG1/13).

Alan during our single interview acknowledged his current need to maintain a continuous bond of attachment to his wife Ethel and his anticipated perception of having to relinquish his '*relationship-self'* in the future:

> I know she died well over a year ago now. I know that the house is still full of *"her*" …her things, but you see I can't bear to get rid of it all [personal effects]. Where do I start? I know what people think, it's like living in a shrine. But it's difficult. She was my wife. We were together for so long. Having her things here makes me feel better. Makes her be here …but sooner or later I'll look back and then …they (*pointing to the personal effects around the room*) will all have to go …I know that (PG1/2).

In contrast, members of PG2, in particular Alex and who were currently caring for their family member with an advanced-stage-experience of dementia, either at home or living in permanent residential care, spoke about their *me-self* as a facet of their sense of self which they felt at present was lost and therefore they were unable to return to. Marie highlighted her perception of her schema of *me-self*, at this point in time, as being irretrievable and contemplated her current and future relationship with her mother and the effect it was having on her overall sense of wellbeing:

> I think that I was conditioned to care *Jo*, that's the whole top and bottom of it. I don't think that she ever loved ME like a mother should and that is a really sad thing to say. I am not sure if she even loved dad or herself for that matter. And now here I am caring for her … In the morning I just "*hit the road running*". When is it going to end? It's no life, no life at all. But how can I change? (PG2/5/c).

Other female spousal members of both groups such as Avril, April, June and Alma, spoke about their acknowledgement of the change in their sense of self, particularly relating to their schema of

me-self whilst having undertaken or continuing to undertake their caregiving journey. June highlighted this by stating:

> …I suppose I have thought about, you know after he, Sid, has gone. …I will be able to get back to doing things for me, but I won't be me …like I was when we first married. Well it's nearly sixty years! You change. We all change. But I wouldn't change a thing, caring for him and the family and that. I will just have more time for me I suppose (*tearfully*) (PG/2/c).

For these participants, returning to whom they perceived themselves as being, their core sense of self was not possible and, more importantly, something which they felt would negate their loving and *relationship-self* with their respective spousal partner.

4.3.3. Being in the Moment

Other participants also expressed how they had independently introduced more mindful activities which they had chosen to pursue within the family home. These activities were reported as being introduced during *"the long road"* and latter stages of their caregiving journeys and for members of PG1 continued into the post-bereavement period. In undertaking these activities participants felt that it enabled them to be present within the moment and to be with their family member, whilst simultaneously reflecting on past memories as a strategy to re-orientate their schemas of self within the landscape. Twelve of the thirty participants involved with this research study spoke about writing poetry, or making regular entries in their diary or personal journal relating to their sense of self and their caregiving role. All of the participants, who spoke about writing as an activity to express their emotions, openly shared their poems or some of their diary entries with me during the course of our interviews. However, the majority of the participants requested that their compositions were not to be documented in this research thesis, given that the content was of an extremely personal nature. During our first of three interviews Bill shared his return to writing poetry as a strategy to assist him in caring for his wife and as an activity to maintain his own sense of wellbeing by saying:

> I always wrote poetry. When we were first married I used to leave little '*ditties*' for Mary to find. I hadn't done that in years, but now I sit and it just flows out of me. Poems about her, poems about us; then I read them to her … she likes that you can

> tell and it really helps me. It helps me to keep calm. You have to keep calm *Jo*, because you can't go rushing around all the time; it's not good for you. But sometimes you have to put your own health needs "*on the backburner*" (PG2/10/c).

Members of PG1 also spoke about entries in their diaries and composing reflective pieces which they felt helped them to express their experiences during their journey and also, for some, after their caregiving journey had ended. For example, at the end of our exploration of her caregiving journey Maggie stated:

> After Si died so suddenly, even though I knew it was coming at some point *Jo*, I needed to "*let it all out*". So, I began to write down my feelings; the things I had done, the things which had helped me … and him really (PG1/16).

Reflecting on her entire caregiving experience and particularly relating to her schematic *me-self* Maggie recited a poem she had written whilst caring for her husband Si, entitled *"Journey"*:

Journey

Little friend from childhood days,
when we had our dolls and played.
The sound of water splashed at that pool
where we danced and laughed and sang.
Life has taken laughter away
we have no time to stop and play.
Women now, we bear heavy loads
as we journey down this long, long road.
Please little friend,
oh can we find that magic pool.
And for just one day,
take our children now to splash and play.

Maggie stated that this poem was written during *"the long road"* period of her journey of caring for Si. A period, as highlighted by all of the participants, as being the most challenging part of their journey, during which their schemas of self were perceived as being continuously challenged. Post-bereavement Maggie spoke about her continuation of writing as a strategy through which she could "*let it all out*", enabling her to express her emotions and feelings of her experiential loss. For several years she has been a member of a women's health group within her local community, which she has found to be extremely beneficial in coming to terms with her loss. She asked if she could read part of a piece of her reflective writing entitled "*The Coat"*, which had subsequently been published in a compilation of writing by women in 2007. She went on to explain that she had bought Si a particular coat which could easily be spotted when she was out with him in the market, in their local town. Describing that this was a strategy she adopted to enable her to "*keep an eye on him*", so he could walk around the market on his own, which he loved to do:

The Coat[29]

> I had been looking for the coat for over two hours … My granddaughter and I were too distraught to notice, we must catch sight of a special coat we had seen disappearing into the milling crowd. … I could picture him wearing it like the winter uniform of an officer, marching along, yet not knowing where he was going. … He was found walking out of town. As the police car took us towards him I recognised the coat that covered the man. For decades he had been my husband, my rock and my love. He now looked so bewildered, like a little boy who had lost his mother. I was now becoming his mother, to comfort and protect him. …Alzheimer's disease had so cruelly robbed us of our golden years, eating away his brain, but it didn't kill him. The large aneurysm in his chest, like a ticking time bomb, one day exploded and he dropped down dead in front of me. But on that much earlier day, he pulled us both to him.

[29] This is an abridged version of a much longer composition written by Maggie (PG1/16).

This piece of writing not only highlights Maggie's attempts to maintain a sense of independence for her husband, but also highlights the transition of her schemas of self, from whom she felt she had been, to whom she perceived she had become in relation to Si.

As previously discussed, members of PG1 and PG2 spoke about the ritual inclusion of photographs as a conduit of connection with their family member, who had died or who is currently living in residential care. However, George had taken this activity further in the compilation of a montage of photographs and other tactile memories of his wife, Mabel. He stated that this collection was a tremendous comfort, both during the latter parts of his caregiving journey and now after her death:

> She was my sweetheart, then my wife, the mother of our children and then I cared for Mabel for so long. I started this when she went into permanent care [pointing at an A3 size montage of photographs]. It helped; it helps to keep her with ME, inside (*pointing to his chest*). Over the years I've added bits and pieces to it. Drawings by the grandchildren, her pressed flowers – she loved doing that. The notice of her death from the paper, photos of the dogs we have had over the years you see. This is the last picture of HER right here (*pointing and smiling*). It's a comfort to me when I can't get up to the cemetery. I try to go each week with the family. But this picture is my private picture, my keepsake of Mabel. It keeps her close (PG1/13).

During the exploration of their landscapes of care only two participants, Joyce and Marie, the two adult-caregiving daughters, did not refer to having previously engaged or stated that they were currently engaged in any activities external to their current caregiving roles. Their overall sense of wellbeing related to their perceived distant horizons and their enduring role of caregiving.

4.3.4 Summary of the Orientation of Self and Wellbeing within the Landscape of Care

This third and final stratum of the landscape of care, the '*orientation of self and wellbeing within the landscape'*, builds on the expansive topographical terrain and the emotive conversational experiences of change, grief and loss explored within the 'communicative *landscape'*. Within this third landscape participants reflected on their past and current strategies of navigation and re-orientation in relation to their perceived schemas of *me-self, caregiving-self* and *relationship-self*.

They spoke about thematic aspects of physically "*getting out and about*", with the majority of the male participants highlighting activities which were undertaken independently of their caregiving role. In contrast, female caregivers spoke about being part of activities and events which involved other caregivers, family members, as well as their cared-for spousal partner.

An additional feature of the orientation of self and wellbeing experienced and referred to by participants included the emotive aspects of their perception of either relinquishing, or their continued wish to maintain their "*ties of attachment*" with their spousal partner or parent. This aspect specifically related to their schemas of *me-self* and *relationship-self.* Nearly half of all participants of both groups interviewed spoke about mindful and personal activities of enabling them to achieve a feeling of "*being in the moment*", whilst reflecting back to past horizons. These activities relate to documenting their emotions and feelings which they had, or were continuing to undertake independently within their own home. Examples given by participants were associated with the writing and reciting of poetry, as well as composing entries within their personal diaries and journals. One female participant had progressed her writing further in becoming an active member of a women's health writing group, which she has found to be extremely beneficial to her schemas of self and wellbeing. Conversely, the post-bereavement approach of one male participant to maintain his sense of self and emotional wellbeing through photographs and tactile memories of his wife was undertaken in private. The two adult-caregiving daughters involved with this study were the only participants who did not refer to any activities undertaken independently or otherwise.

4.4 Review of Chapter Four

This chapter has highlighted an exploratory interpretation of the expansive landscape of dementia care, during which participants spoke from three interconnected and fluctuating schemas of self. Firstly, with regard to the schema of *me-self,* the self participants perceived as their core and envisaged sense of self. Secondly, their *relationship-self,* illustrating their bonded connection in relation to themselves and the cared-for spousal partner or parent, as well as other family members and care workers. Finally, the aspect related to participants' *caregiving-self,* associated with the acquisition and undertaking of their role of familial caregiver. The emergence of this conceptual

framework intersects with the application and adaption of the theoretical framework of anticipatory grief and loss by Fulton and Fulton (1971) and, Fulton and Gottesman (1980) across the entire landscape of care to formulate a tri-dimensional and stratified framework.

The first stratum of this tri-dimensional framework explores the foundational and expansive '*topographica*l *landscape'* which highlights psychological and divergent experiences of caregiving, which commenced with participants' perceptions of a "*who we were*" period in relation to their cared-for family member. Then moving to more generic periods of dementia care, during which participants highlighted their experiences of pre- and post-diagnosis, as well as experiences of accessing services. Participants then emphasised a protracted middle period which they defined as being "*the long road*" period of their journey. This was the period which members of PG2 perceived as being their current and continuing part of their journey. The latter periods of caregiving with regards to palliative and end of life also highlighted differential retrospective experiences for members of PG1 and prospective perspectives for members of PG2.

Threaded throughout this foundational landscape, participants expressed their experiential emotions and feelings relating to four of the non-linear five *grief-tools* outlined by Kübler-Ross (1970) and Kübler-Ross and Kessler (2005), namely anger, depression (feelings of isolation), denial and acceptance. The remaining *grief-tool* of bargaining is highlighted within the second strata of the landscape of care, namely the '*communicative landscape'*. This second layer of the landscape offers a textual representation of oral (spoken and unspoken), as well as written forms of experiential emotion and expression perceived by participants as either positively accentuating or challenging their interconnected schemas of self. In addition, participants reflected on conversations which they had not undertaken, or were unable to undertake during the course of their individual journeys. The dominant actual and perceived expressions of emotion and feelings within this second stratum related to participants' experiences of "*love*", *"empathy*" and maintaining a sense of spiritual "*connectedness"*, which participants found to be not only comforting, but also a reinforcement of their schemas of self. However, the exploration of this communicative layer of their landscape of care also highlighted those conversations which appeared to be ambiguous and at times challenging to participants' self schemas, culminating in feelings of "*guilt".*

The third and final stratum of the landscape of care relates to the participants' '*orientation of self and wellbeing within the landscape*'. Highlighting strategies and routines previously undertaken or continuing to be undertaken during the latter periods of the caregiving journey; which participants of both groups perceive as assisting them to navigate and re-orientate their sense of self in response to their experiences of change and loss. Strategies and routines expressed by participants related to previous and current physical activities of "*getting out and about"*, as a way in which they could regain and retain their schema of *me-self* and assisting them to continue with their caregiving role. Participants also spoke retrospectively and prospectively of their wish to maintain their "*ties of attachment*" with their spousal partner or parent. This aspect specifically related to their schemas of *me-self* and *relationship-self*. Nearly half of all participants of both groups interviewed spoke about mindful and personal activities undertaken to engender feelings of "*being in the moment*", whilst reflecting back to past horizons.

Chapter five, the penultimate chapter of this document, discusses the essence of experience associated with dementia caregiving, focussing on the emergence of the conceptual framework relating to the fluctuating perceptions of self of family caregivers involved with this research study. In doing so it attempts to understand the caregiving experiences of change, grief and loss vis-à-vis the differences and similarities of current literature.

Chapter Five: Self and Being within the Dementia Care Landscape

5.0 Introduction

> As in play, it rests on a common willingness of the participants in conversation to lend themselves to the emergence of something else, the *sache*[30] or subject matter which comes to present and presentation in conversations (Gadamer, 1975: 262).

This chapter discusses the consistent themes recognised in previous dementia research relating to periods and events experienced by family caregivers during their caregiving journey. Nevertheless, the overwhelming feature of this study identifies the emergence of the conceptual framework of the fluctuating perceptions of self experienced by family caregivers across the entire landscape of care, which to date has not been reflected in other literature. In addressing the aim of this research study the contents of this chapter attempts to understand the retrospective and prospective caregiving experiences of twenty eight spousal caregivers and two adult-caregiving daughters, from dementia diagnosis to final bereavement.

With the vantage point of hindsight and through the lens of reflexivity, I would like to suggest that initially we often view journeys we have undertaken within the expansive proportions of their entirety. Enabling us to comprehend, or indeed not as in some cases, the complex composition of our episodic experiences, conversations and emotional responses to situations as they developed or after they have happened. Within our acts of reminiscence we may perhaps subconsciously create a schedule of our life-world experiences, which are emotively punctuated by happy and sad events, beginnings and endings, wishes and regrets. I further argue that we may also be cognisant that as one journey ends, it merges into anticipated future journeys which we may choose to commence. Alternatively, they may be viewed as journeys we are reticent about and therefore wish that we did not have to undertake. My role as researcher is to comprehend not only the life-world existentials

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[30] *Sache* is the German word for '*sake*' denoting: 'as in the thing itself', http://dictionary.reverse.net accessed 22nd November, 2015.

of the research participants involved with this study, but also to convey a hermeneutic phenomenological interpretation of their thematic life-world and dementia caregiving experiences as a whole.

5.1 The Schematic Experiences of Self and Being within the Landscape

From a hermeneutic phenomenological perspective van Manen (1990) suggests we experience our life-world from within four differentiated, yet nonetheless interrelated existential perspectives. In relation to the lived-world of the participants involved with this research study this specifically connects to the geographical space, the stratified spatiality of their caregiving landscape. It is also associated with participants' perception of their physical being within this landscape and the way in which they have previously shared, or are currently continuing to share this space with others. These others are not only the cared-for-person, but other family members, as well as interpersonal relationships with health, statutory and voluntary sector care workers.

This landscape encompasses participants' perceptions of being in their lived-world of caregiving and their transference of temporality of incorporating their past, present and future horizons (van Manen, 1990). Temporality is also purported by Parkes (2006), who offers the concept of the *assumptive world*, which he argues as relating to the decisions we undertake which may supplement, or contradict previous experiential views of our reality. The experiences of the participants involved with this study highlight a world which is not fixed, but constantly requiring review, negotiation and change, enabling them to navigate the complexities and ambiguity of their landscape of care. As previously discussed Gillies (2011) highlights that the journey of dementia care is undertaken within the *"shifting ground of a progressive illness*" (ibid, 657). A world in which family caregivers often experience changes relating to their sense of being and self.

With regard to our sense of being in the world, I concur with Sills (2000) who asserts that our '*being*', the overall sense of who we are is dependent upon at least one essential other, which he describes as the existence of an "*empathic touchstone"*. For the participants involved with this study this essential other is the cared-for-person, their spousal partner or parent. In addition, from an interpersonal perspective, participants also spoke of inter-relationship experiences with

additional family members who were either involved, or not involved with the role of caring for their family member with dementia.

In terms of our perception of self I agree with Rogers (1980), who suggests that it is through interpersonal discourse with others that our experiential view of self is a continuous movement of change. Our sense of self, he argues, not only relates to our adjustment to periodic experiences over the course of time, but also responds to moment-by-moment encounters. The fluctuation process of the three schemas of self presented and interpreted with regard to the experiences of study participants reflects an unremitting movement within their perpetually changing landscape of caregiving. This process encompasses their past and present experiences, as well as anticipated future outcomes in relation to change, grief, loss and bereavement.

I began with the participants' identification and perceived view of their schema of *me-self* as being their sense of self which they view as their essential core essence of being. This was often articulated as the self that they wished that they could to return to, or that they felt that they had, through the duration of their journey and the acquisition of other roles appertaining to caregiving, become disenfranchised from and had lost completely. Nevertheless, some participants attempted to maintain a sense of their individual *me-self* in the undertaking of activities within and out-with their caregiving role. The second self, the *relationship-self* is associated with their interconnected relationships with the cared-for-person and other family members. This schema of self also relates to interpersonal relationships and dialogues with others outside of the family, such as other family caregivers, clinicians and care workers. The third self, the *caregiving-self* relates to participants' positive and, for some, negative experiences relating to their caregiving role within and beyond the family environment. This tri-model representation of the schemas of self occurred within a continuous state of interaction of past, present and anticipated future experiences. However, unlike the core *me-self*, the latter two senses of self, the *relationship-self* and *caregiving-self*, were afforded interpretative precedence by caregivers during the course of our exploration of their individual landscape of care.

5.1.1 The Roots of the Me-self and the Relationship-self

During the course of our examination of their individual journeys, all of the participants reiterated an oscillating itinerary within their caregiving landscape, from their recognised beginnings, to where they felt they were to date. In retracing and exploring their journey, participants spoke from within definitive periods or stages, but also highlighted complex experiential events and their emotive responses, which then fused some of these periods together telescopically. In the presentation of their subjective experiences of their journey, participants' sense of self continuously moved backwards and forwards. However, during the course of the interview process participants would often momentarily pause and reflect, but then would also appear to accelerate their reflective descriptions when talking about happier events and *"sunny"* moments of day-to-day living. In contrast, they also appeared to reduce speed when highlighting their individual stories to exemplify the occurrence of "*darker*" days, months and even years within their individual journeys.

As I have previously discussed in chapter one of this document, the definitive term that I have used in relation to caregiving undertaken by participants is that of their experiential journey. However, regardless of the fact that we commenced the start of our exploratory conversations with the '*grand tour'* question of "*please tell me about your journey*", all of the thirty participants initially guided me across the threshold into their landscape of care by offering a graphic background description of a "*who we were*" period. They presented their perceived schema of self, not only vis-à-vis the person with dementia, but also with regard to themselves and their immediate family members.

The scenic depiction of this period enabled us to look back to past horizons, in exploring and interpreting who participants perceived themselves as being in relation to their schematic *me-self.* Also highlighted in this far distant period of their journey was the establishment and maintenance of their bonds of attachment with not only the person with dementia, but also other family members. For spousal participants of both groups, this reflection transported our exploration back four to six decades, in which they offered expressions of who they perceived themselves as being. Scenes were interwoven with happy and emotive memories such as meeting their spousal partner and the establishment of the schema of *relationship-self* with their husband or wife. In addition, work commitments, holidays and for some participants the birth of their children and family life

were aspects of their lived-world which were also highlighted. The emotive tenet of this period related to their overall expressions of love, which permeated the subterraneous topography of their landscape. It was also a period when the person with dementia was described as being young and physically and cognitively fit, as well as the collective day-to-day life experiences of their individual families and beyond. The spousal participants also reminisced about a time in their lives which was full of hopes and dreams for an anticipated life together.

From the perspective of temporality, the lived-time experience, van Manen (1990) cites Otto Bollnow (1988), who describes this period as being the '*mood of life'*. Bollnow defines this period as encompassing the expectations of youth, akin to the *'morningness'* of a new day. Utilising the climatic definitions offered by the participants during our exploratory conversations, I would like to describe this beginning as their '*spring time'* within their life-world landscape. This was a season in which participants described the roots of their schematic *me-self* and *relationship-self* with their spouse as being a harmonious and equitable partnership. Nevertheless, they outlined relationships which also had specific gender delineation associated with the undertaking of roles and responsibilities within their family. Given the age range of the spousal caregivers involved in this research study as being between 60-85 years of age, the day-to-day activities of caregiving within the family, during this early period, were invariably acknowledged as being undertaken by women. This concurs with the interpretation relating to women and caregiving, as argued by researchers such as Calasanti and Bowen, (2006); Campbell and Carroll (2007); Paoletti (2001), that it is a role *'given'* to women and a definitive characteristic of their self-identity.

However, male spousal participants spoke of their acknowledgement as to the caregiving role previously undertaken by their wife within the family. Relating how this subjectively compared to their perceived view of their subsequent role of caregiving, previously assumed in their distant past by members of PG1, or continuing to be undertaken in the present by members of PG2. With this acknowledged comparison several of the male participants, such as Alan, reflectively expressed their emotive feelings of guilt that perhaps they "*didn't do it right*". These emotive expressions were not necessarily attributed to their response with regard to the physical and cognitive changes of their family member, as reported by Ducharme et al., (2013), but related to the participants' perceived self-doubt in their own abilities in having been unable to appropriately provide reciprocal

care for their spousal partner. This was something which they each stated that they had adamantly wished to undertake from the outset of their caregiving journey and had wanted to continue to do so for as long as their own physical fitness would allow. Spousal partners did not express the *'closed'* situation of the reality of caregiving as purported by Bender (2003). They did not wish to leave their perceived responsibility, but as with spousal caregivers such as Jessie, they did refer to feelings of isolation and loneliness within their marital relationship, especially during protracted periods of their journey.

For the two carer-daughters, Joyce having formerly undertaken her physical caregiving journey and Marie continuing to do so, both spoke of the "*who we were*" period as commencing some fifty seven years prior to being interviewed. Beginning with the role of caregiving undertaken by their parents within the family, they then moved the conversation forward in briefly highlighting their experiences of childhood, family time and their own progression into adulthood. Joyce spoke of her awareness and acceptance of being a "*caring daughter*", whilst Marie highlighted her perception of not only being a caring daughter, but also being "*conditioned to care*" from a very young age. In doing so each of these women offered divergent views of their schematic representations of *me-self* and *relationship-self* with respect to their respective mothers, their cared-for family member. Nevertheless, they both expressed their perceived requirement and wish to act as gatekeeper in supporting and accessing dementia-related information and practical support services on behalf of their fathers.

During the early periods of their journey spousal participants involved with PG1 and PG2 also presented former reciprocal examples of care. Highlighting the support they had previously received from their cared-for family member, during experiential periods of their own physical ill-health. As previously discussed, Stalker (2003) suggests that whilst caring relationships may often be perceived as burdensome, they may also display mutual aspects of reciprocal interdependence. However, for spousal participants having undertaken their caregiving role, or still continuing to do so, this was an acknowledgement of enabling them to reciprocate the care that they had previously received from their partner in the past. These examples of reciprocity echo the research of Tronto (1993), who state that during the course of our lives we experience varying degrees of dependence, and interdependence within our inter-personal relationships. Yet, all of the spousal

participants involved with this research study referred to reciprocity within the context of a three foci time period. They reported that their experiences of reciprocity were not only being undertaken within the present, but also the past and with regard to future anticipated requirements of caring for their family member. This reciprocal bond of care threaded across the entire landscape tapestry, and was again cited as experiential expressions of love for the cared-for-person by each of the participants.

For the spousal participants of PG1 and PG2 this resonates with the work on Alzheimer's disease and marriage undertaken by Lore Wright (1993). Participants continuously offered expressions relating to their *relationship-self* in their attempts to preserve the marital bonds of "*in sickness and in health*", which they had made to their spousal partner in their far distant past. For participants of PG2, who were actively caring for their family member, this was also expressed in their wishes to maintain this commitment now, and into the future. The acknowledgement of their commitment to care was also pertinent in the reflections offered by the two caregiving daughters. Who, although citing a further enhancement of their emotional relationship in supporting their father in caring for their mother, as highlighted by Netto, Jenny and Philip (2009), also expressed their realisation that they felt unable to escape from their caregiving role. Nevertheless, they continued to do so out of the child/parent bond of love for not only their mother, but also their father. Although this bonded commitment to supporting and caring for their father was also anticipated as a further caregiving journey, which they may have to undertake in the future. A journey which was predicted by both participants as involving not only potential and deteriorating consequences in relation to their respective father's physical health and mental wellbeing, but also their own. In addition, they highlighted that this impending journey may also impact on their own marital relationships, requiring the possibility of negotiating further support from their respective husbands.

5.1.2 The Coalescence of the Relationship-self and Caregiving-self

Set against a backdrop of perceived familiarity and the ongoing day-to-day routine of life comprising a clear delineation of roles within the family, the pre-diagnosis and perceived start of the dementia caregiving journey elucidated memories, for some participants, relating to the realisation of change and the encroachment of "*something going on",* being experienced by their

family member. These experiences emphasised an apparent concern for the majority of spousal caregivers and for Marie, one of the caregiving-daughters. In contrast, several participants of both groups spoke about their initial lack of awareness relating to the cognitive difficulties being experienced by their spousal partner. Conversely, participants and their cared-for family member who had sought confirmation resulted in prompt visits to their GP in relation to possible explanations. This differs from the findings of Adams (2006), who states that spousal caregivers and adult-caregiving daughters in an attempt to maintain the normality of family life were often reticent in seeking assistance from clinicians. However, efforts to maintain the normality of family life by participants in this study were reported as being specifically undertaken during the protracted middle stage, *"the long road"* period of their journey.

During the post-diagnosis period, participants echoed the findings of Kitwood (1997) and Purves (2010) in their reporting of the re-negotiation and repositioning of roles and responsibilities within the family unit. Although a minority of spousal wives found the transition of taking on new roles and responsibilities, which had previously been undertaken by their husbands, to be a challenging experience. This is also reflected in the research by Furlong and Wuest (2008) who report on the lack of self-care undertaken by older caregivers. Nevertheless, participants involved with this study also reported change experiences which included an adjustment of their perception of *relationship-self* within their marriage and their subsequent transition of having been cared-for, to becoming caregiver to their spousal partner. For the spousal caregivers who had obtained clarity relating to the cognitive changes being experienced by their partner and a definitive diagnosis of dementia being received, the role of caregiving was then considered by many as an extended feature of their bonded relationship. Although several female members of PG1 and PG2 chose to *"cope"* and to maintain caregiving within the boundaries of their marital relationship for as long as possible, before seeking practical support provided by external agencies or even other family members.

For other male and female participants of PG1 and PG2 the perceptual awareness of "*something going on*" and the emergence of their schema of *caregiving-self* appeared to be less clear. This was due to a number of factors, relating not only to their admission of a lack of awareness as to the memory impairment and cognitive deterioration being experienced by their family member, but also invariably to the complexity of previous and on-going health issues being experienced by their

cared-for relative. This latter experience culminated in an overlap of the additional routes and pathways of healthcare being accessed by the cared-for-person and their family.

Transparency relating to a conclusive diagnosis of dementia for these participants was often acquired after an explicit crisis event or, as in some cases, prolonged over a number of years due to lack of relevant information and being directed to other available avenues of support. This differential route thus added to the confusion experienced by the caregiver and the cared-for-person in finally receiving a confirmed diagnosis of dementia. Nevertheless, for the majority of participants, the events of pre-diagnosis and the subsequent receipt of a diagnosis being given often merged within the sequence of events explored during the interview process. Yet, for some participants involved with this study, who had a positive experience in seeking a dementia diagnosis from their general practitioner, it was the next step in the caregiving journey and being referred on to other clinicians, which consistently proved to be negative. These experiences related to the overall lack and continuity of communication, which for older male participants in particular, was perceived as perpetuating during pivotal periods across their entire caregiving journey.

This was also the point of the journey in which spousal participants revealed a significant loss and end of their anticipated hopes, dreams and plans for the future. Looking back over this period all of the participants who had been in receipt of a prompt diagnosis of dementia regarding their family member stated their acknowledged, although reluctant acceptance of the beginning of the cognitive changes being experienced by their relative. They also recognised the necessity as to their own re-adjustment in response to these losses. In doing so participants illuminated the beginning of expressions of anticipatory grief as to possible experiential losses for themselves, their cared-for relative and other family members in the near and distant future.

Participants' overall description of this period was associated with their realisation of having to commence an emotive process of adaptation, which concurs as Rando (2000) suggests, in response to their anticipation of experiential grief. It was the period in which participants, again albeit reluctantly, began to initially embrace the anticipated reality of the cognitive and, in some cases their perceived physical loss of their family member, whilst at the same time addressing the psychological challenges of relinquishing part of their held image relating to the "*who we were*"

aspect of the relationship, which they had previously experienced with their spousal partner or parent. In the emergence of their schema of *caregiving-self* and the acquisition of their new role, participants continuously highlighted their attempts to draw closer to their family member and to maintain caregiving within the family home for as long as possible. For the majority of participants this was undertaken over a protracted period of several years, often with the support of external services and the involvement of other family members. Yet, as with other participants their experience was referred to as being part of the long and arduous task of caregiving. A task which they anticipated would take them further into an unknown and ambiguous territory.

Participants then moved forward in their reflections, to speak about their post-diagnosis responsibilities as being a negotiated balance in relation to a change in lifestyle within their immediate family. They outlined their further realisation and requirement of undertaking new roles and responsibilities, which they felt had been previously assumed by their marital partner or parent. Some of the participants emphasised the support they received from other family members. With regards to spousal caregivers this related to the provision of supportive care offered and undertaken by their children. However, other participants also stressed that it was other members of their family and not themselves, who had initially expressed feelings of denial with regards to a formal diagnosis of dementia being received. These family members were highlighted as being their adult children or siblings, who did not live within the immediate locality. Participants perceived that the expression of denial by their family member was due to their relatives' lack of awareness relating to the cognitive changes in the health of the cared-for person, as well as to the day-to-day realities and challenges of the caregiving role.

However, for some participants, an overwhelming emotive expression emphasised during this period related to anger. Specifically, this was with regards to their negative experiences concerning their interactions with clinicians and hospital staff. The consequences of which resulted in an awareness of not being in a position to access relevant information and appropriate external support. This was then cited as being the causal factor of recurrent feelings of not only anger, but also perceived expressions of guilt by participants. These subterraneous emotions then proceeded to reverberate across their entire landscape of care. For the majority of participants, our conversational exploration followed their care path towards practical information and medical

support, which was far more direct and conducive for them in acknowledging and accepting the third schema of self, the *caregiving-self*. This led to the development of clear routes of care and the establishment of a parallel provision of practical support offered by the Alzheimer's Society and other health services, being offered to the caregiver and the cared-for-person.

Spousal caregivers, such as Maggie for example, did express their acceptance of their caregiving role and their undertaking of accessing services provided by their local branch of the Alzheimer's Society. This was specifically with regards to attending peer support group meetings. Yet in seeking support outside of their caring relationship, several female participants again made a conscious decision not to involve other family members at this point of the caregiving journey. The inclusion of family members in providing caring support to these caregivers subsequently occurred after a pivotal crisis event involving the cared-for-person, or following periods of ill-health experienced by the participant themselves. Other spousal caregivers, such as Patricia and June, accepted and assumed the anticipated practicalities of their future caregiving role, although not the acquisition of the label of carer. Concurring with Netto, Jenny and Yap (2009), a minority of female spousal participants reported this descriptive term as being a totally inappropriate representation of who they perceived themselves as being. Their preference was to be considered as being firmly rooted and referred to within their spousal-partner relationship with the cared-for-person. The person whom they expressed that they not only cared-for, with regards to the practical aspects of dementia caregiving, but also emotively cared-about, given their enduring relationship with their partner. Throughout their reflection of their caregiving journey these participants reported that they felt that their schema of *relationship-se*lf was continuously challenged and their self-identity was therefore persistently eroded. This they stated was due in part to the growth of the accepted societal view of caregivers. Especially by clinicians in recognising spousal partners in providing care to a person with dementia, simply as being the designated carer of that person. Participants continuously expressed their perceived view of not being personally acknowledged as either an individual, or as part of a marital couple.

In continuing the exploration of their landscape of care, the majority of participants progressed to a period in which they had chosen to access other additional services on a regular basis. These services related to the provision of support within and out-with their family home environment.

Early examples highlighted the introduction of support from domiciliary care workers, working for the local authority in providing assistance with the daily tasks of caregiving. Spousal participants, who were in receipt of these services, saw this as a means of extending the continuity of their caregiving role within the home. In addition, it was also welcomed as a way in which both they and their spousal partner could enjoy the company of other people, which extended beyond their day-to-day lived-world experience. Predominately the accessing of services which were referred to outside of the home, were those offered by the Alzheimer's Society within the locality. This often involved the person with dementia attending day care services or luncheon clubs. Participants felt that these particular services were not only conducive to the wellbeing of their family member, but also afforded them the opportunity of brief periods of respite away from each other. As previously discussed, an example of this was highlighted by April who, with regards to her husband, stated that "*it was good for Billy to have a break from me*". However, for participants living within rural communities, the accessing of services for either themselves or for the person with dementia proved to be far more challenging. This particularly related to issues with regards to lack of public transport in rural areas, which negated participants' involvement with these services on a regular basis. These participants spoke about the beginning of feelings of isolation and the stress related issues of caregiving, echoing the research of Burns and Rabins (2000) and Mikulincer and Shaver (2008).

There were also negative aspects experienced by participants relating to their spousal partner attending day care services. Patricia for example, as with other participants, reflected on numerous occasions when they had to persuade their spousal partner to attend, or even physically take their family member to the day care venue. This reflects the exploration of the caregiving journeys of spousal male caregivers undertaken during my MSc research study (Alexjuk, 2007). During this earlier study, the six participants expressed that psychologically the most demanding part of their caregiving journey related to the period when their spousal partner was physically fit and active. This was when their family member was living at home and accessing day care and weekend services provided by the Alzheimer's Society. Likewise for participants of this current study, these challenges specifically relate to behaviour, as highlighted by Knapp et al., (2007) and Hughes (2011). Participants reported that they found these new and out-of-character behaviours exhibited by their family member to be extremely challenging. Behaviour which they felt often negated their

attempts of being able to achieve even short periods of respite and "*me-time"* on a day-to-day basis which they nonetheless felt was a strategic and necessary process in assisting them to further continue their caregiving role within the family home.

In addition, participants involved with this study also outlined the recognition of the requirement for "*me-time"* undertaken outside of the support services offered by the Alzheimer's Society, especially in accessing short respite breaks facilitated by their local authority. This was specifically reported by male spousal participants, such as Eric, who chose very early on in his caregiving journey to remain in contact with his former work colleagues and friends. This he saw as a way to maintain his *me-self,* his own self-identity, whilst continuing to care for his wife at home. Nevertheless, breaks away from the caregiving role, undertaken by male participants who opted to do this, were often predicated on the support offered by family members. Alternatively, it necessitated the involvement of local authority care workers in remaining with the cared-for-person within the family home, or the accessing of longer respite breaks for their partner within a care home environment. The joint accessing of other services was also reported by caregivers with their cared-for relative, such as attending Alzheimer's cafés and luncheon clubs. However, male participants who did access services together with their spousal partner, such as Roy and Bob, expressed that perhaps these meetings were not personally beneficial for them. Nevertheless, they continued to attend to enable their wives to socialise with others and to experience time outside of the family home.

In contrast, some female spousal caregivers continued not to seek or to access support services on a regular basis, for either themselves or their family member. This was often related to their wish to independently cope with their caregiving role, which linked to their bonded *relationship-self* with their marital partner. For others it was due in part to the person with dementia being unwilling to have support within and out-with the family home, for either themselves or the family caregiver. Consequently, for these participants for example Jessie, the experiential depletion of external contact with family and friends outside of the day-to-day tasks of caregiving, were viewed as having incremental repercussions. In response to these experiences participants cited this period as the beginning of their concerns relating to feelings of loneliness, as previously reported by Brodaty and Luscombe (1999); Cascioli et al. (2008); Millán-Calenti et al. (2000), and a deterioration in

their own mental health, as reported by Peacock, Hammond-Collins and Forbes (2014). Their schematic sense of self fluctuated between their expressed wish to maintain their own self-identity and their *relationship-self* with the cared-for-person. Whilst also attempting to achieve a balance relating to their own healthcare needs and the anticipation of continuing with their caregiving role.

Conversely, other participants, especially female participants for example, spoke about being able to achieve a balance of self within their lived-world experience at this time. Their schematic representations of *me-self, relationship-self* and *care-giving-self,* at this point of their caregiving journey, appeared to be calmer and a relatively non-fluctuating activity. This they felt was attributed to several factors which included family involvement and positive experiences of being able to access support services from the very beginning of their journey. Their experiences specifically related to their attendance at peer support group meetings with other family caregivers. In joining these meetings participants reported the sharing of practical and emotional support experienced by other caregivers, as well as helpful guidance to specialised services offered by other agencies, as suggested by Alzheimer's Society care workers. However, the overall support relating to the emotive aspects of caregiving, outlined by participants of this research study, was reported as being predominantly addressed by other caregivers involved with these peer support groups. Lucy, Molly and Sheila, the "*carer support group girls*" and members of PG1 for example, highlighted that their individual caregiving experiences appeared to run in direct parallel to each other, enabling them to discuss their emotional experiences of being in the "*same boat"*. Although acknowledging the seeking of practical support in accessing other services, such as extended periods of respite care during the course of their caregiving experience, was often arranged with the support of the Alzheimer's Society and other external agencies.

5.1.3 Maintaining the Schemas of Self on the Long Road

In contrast to the previous, as well as the subsequent periods of the landscape of care explored by participants and myself, the middle phase evoked experiential memories of being the most expansive and monotonous. It was also perceived by participants as being the most physically and emotionally challenging phase of their caregiving experience. Defined as being a period during which they experienced a fluctuating maelstrom of emotions in response to explicit crisis events,

particularly relating to ill-health being experienced by both their family member and themselves. For the majority of caregivers this was appropriately referred to as being "*the long road"* part of their journey, which they highlighted as extending over several years. For some members of PG1 it was, retrospectively, cited as holistically extending up to the point of the physical death of their spousal partner. Although having various definitive points which they emphasised during the course of our interview conversations to clarify particular aspects of their caregiving journey. In contrast, the majority of members of PG2 expressed their perception of continuing their caregiving journey within this period.

Echoing the findings of Pringle (2003), all participants emphasised the occurrence of "*good days"* and *"good moments"* experienced by both themselves and the person with dementia. Yet embedded within this stage of their journey, they also expressed that there were *"bad days"* and *"bleak days*" of emotional darkness. Creating the ambiguity of caregiving, as previously highlighted by Boss (1999; 2006; 2011), within their moment-by-moment relationship with their family member. In doing so they perceived this period as paradoxically being a time of change, as well as involving repetitive periods of non-change for both themselves and their cared-for-relative. The protracted temporality of their lived-world experience was also paralleled by an apparent deceleration of their narrative reflections, as participants described their emotional responses to events experienced within this timeframe. During our exploratory conversations participants appeared to symbolically linger within this stage of their journey, often returning to this time to clarify issues relating to the prolonged requirements and emotional responses of caregiving. This concurs with the research of Hellström and Torres (2016) undertaken with spousal caregivers and their focus on past horizons which they had previously crossed. Nevertheless, the participants involved with this study also expressed anticipatory feelings of the future and their perceived further loss of their *relationship-self* with their cared-for relative. In addition, they also cited their realisation and concerns relating to their own mortality.

Conversely, some spousal participants of both groups during this period echoed research undertaken by Chappell and Reid (2002) and Sabat (2010) with regards to their perceived closeness with their cared-for relative, as enabling them to achieve a sense of wellbeing as a caregiver. They reported positive feelings of caregiving, as suggested by Brodaty and Donkin (2009), which they

reported as stimulating a sustained resilience relating to the schema of *caregiving-self*. Male spousal caregivers such as Bill for example appeared to experience a *"flourishing"* of his sense of self, (as previously reported by the individual female participant in Sabat's, 2010 research study). Nevertheless, Bill acknowledged that this was only achieved with the provision of additional services provided by local authority care workers within the family home.

In contrast Joyce and Marie, the two adult-caregiving daughters, highlighted differential views of caregiving during this period. Joyce reflected on her schematic representations of *relationship-self* and *caregiving-self* with regard to her secure bonded relationship with her mother. Ward-Griffin et al. (2007) define this cohesive relationship as being a *custodial* and *cooperative* experience for both the caregiver and cared-for person. Conversely, Marie expressed her perception of a continuous and emotionally charged relationship with her mother. This type of dyadic relationship is one which Ward-Griffin et al. (2007) argue is an example of being *custodial* and *combative.* The foundation of Marie's daughter-mother relationship is based on her perception of possessing an insecure bond of attachment with her mother, and an overwhelming awareness of always having to undertake the provision of support for both of her parents. Marie's expressed experiences reflect the concept of an emotionally '*parentified*' child, as suggested by researchers such as Engelhardt (2012); Hooper (2007a); Katz et al. (2009). However, both Joyce and Marie openly expressed feelings of love for their parents, but also their experience of exhaustion and depression, as previously reported by caregivers in research undertaken by Peacock, Hammond-Collins and Forbes (2014).

For some participants this was the stage of their caregiving journey during which empathic conversations with other family members, offering practical and emotional support, was also welcomed and undertaken. In contrast, the experiences of others outlined negative discussions, viewed as being neither supportive nor productive and a challenge to their schema of *relationship-self* with family members. Subsequently highlighting for these participants, such as Rachael and her daughter, and Joyce and her brother, the resurgence and acknowledgement of insecure bonds of attachment they felt that they had with their relative. Other negative interpersonal relationships also happened beyond the family unit. Predominantly, events relating to hospital admissions were reported and in some cases during the reassessment of the person with dementia. The development

of the MRSA infection for example, experienced during a specific period of re-assessment by several people with dementia living within the same geographical area whilst accessing a particular healthcare unit, proved to be extremely difficult for their family members to comprehend. In addition, conversations with hospital staff and further action in the non-provision of comprehensive information being offered regarding the treatment of the infection, added to the confusion experienced by the participants.

Male and female participants also spoke of their attempts in trying to maintain the ordinariness of family life, highlighting special anniversaries being celebrated and family holidays undertaken at the beginning of this period. In contrast, for others it was also cited as a period permeated with the occurrence of further out-of-character behaviour being exhibited by their family member. Behaviours which they found to be challenging, yet for some they were experienced and independently endured, preferring to choose strategies to tackle these incidences without seeking the intervention of other family members, or additional support outside of the family home. Other participants highlighted the application of additional strategies as a way to negotiate and to maintain a balance between their own needs, their relationship needs and in providing continuous care for their relative. For some spousal caregivers this involved maintaining religious practices, by both themselves and their partner, which they found to be extremely beneficial. These participants reported that communicating with God, for example, involved praying for and with their family member, but also asking for mental and physical support in being able to continue their caregiving role. Only one participant and member of PG2, Alex, spoke about the application of the *grief-tool* of *bargaining*, as highlighted by Kübler-Ross (1970, 2009) and Kübler-Ross and Kessler (2005). This was interpreted as his wish to maintain his caregiving role, but was also considered in tandem with his perceived "*bombshell*" admission as to whether it would be a relief if his wife died. Yet, as with other caregivers, he negotiated this dilemma by projecting his thoughts forward to the future and anticipating what his life would be like after the death of his wife. Nevertheless, of all of the *grief-tool* related emotions, dialogical bargaining was the least reported during the entire exploration of the dementia caregiving landscape with the participants involved with this study.

Other spousal caregivers reiterated their attempts in re-orientating themselves in the landscape, by seeking solace within more mindful activities, such as commencing or re-commencing the writing

of poetry and keeping a diary or reflective journal. Activities which they felt enabled them to express their experiential feelings, but did not necessitate physically leaving the person with dementia. Physical outdoor activities were also cited as a routine strategy, often undertaken independently, but also related to a way in which they could attempt to retrieve the perceived *'loss'* of their bonded *relationship-self* with their partner. Spousal caregivers reiterated involving the cared-for-person in outings. An example of this was given by Brenda, who talked about taking her husband to places they used to visit when they first met as a way in which, metaphorically speaking, she could enter and be together with her husband in his internal world. As with other participants, Maggie offered an example of a more practical strategy in the application of distinctive clothing, as a way to enable and maintain a sense of independence for both herself and her husband. Although in offering this example she also acknowledges the change of her *relationship-self* with her husband, from being his *'wife*' to becoming his *'mother"*. This change in self-identity of female spousal caregivers is also reported by Ducharme et al. (2013). Male and female spousal participants involved with this study spoke about independently engaging in physical activities, such as walking or shopping, enabling them to take time-out away from their caregiving role.

With regard to anticipatory grief, the overwhelming feature of this period was a negotiated balance in response to an oscillation between *'loss orientation'* and '*restoration orientation'*, as highlighted by Stroebe and Schut (2001) and Richardson (2010). Overall, participants report that their days on *"the long road"* appeared too fused into months and then into years of caregiving. During which they expressed that they began to acknowledge the experience of the unrelenting task of caregiving, as reported by Schulz et al. (1992). Nevertheless, they continued to express the wish of being able to continue to care for their family member for as long as possible within the family home.

Caregiving cited in the next period of their journey, related to permanent residential care, was considered differently by caregivers of both groups. Predicated, as Stevenson (1999) suggests, as to the length of time they had spent caring for the family member. However, from the very beginning of their journey the transition of their relative moving into a permanent residential care environment had not been an option for some participants. Continuous support from family members and the accessing of home-based services, had enabled the spousal participants to honour

their wishes of "*in sickness and in health*", in the facilitation of caring for their relative at home. For other participants who had previously accessed respite services, the negotiation of "*sharing the caring*" with permanent residential care staff was considered as a total relinquishing of not only their schema of *caregiving-self*, but was also anticipated as being detrimental to their perception of their *relationship-self*. Resulting in expressions of loss of what had previously been the dominant feature of their life, the care of their family member. With regards to spousal caregivers, this also resonates with the perception of an '*uncoupling*', as suggested by Chene (2006) and an anticipated liminal state of '*quasi-widowhood'*, as highlighted by Rosenthal and Dawson (1991).

However, for Joyce, the caregiving daughter, this period illuminated another aspect. In her reflection of the consideration of surrendering her full-time caregiving role, Joyce had perceived that this would be the abandoning of her mother. In doing so she expressed that she would have metaphorically "*lost*" her mum before the actual physical death of her mother occurring. It was also interpreted by Joyce as severing the strong bonds of attachment with her mother, resulting in Joyce's anticipation of being in a state of "*semi-orphanhood*", which paraphrases the research of Rosenthal and Dawson (1991). In addition, Joyce also expressed another factor, again associated with interpersonal attachment. This being her wish to continue to support her father in his caregiving role, thus, she perceived, shielding him from experiencing a separation of his *relationship-self* appertaining to his wife. Nevertheless, this had proved to be an emotive decision within the family, particularly with regard to her discussions with her brother.

Yet for other participants, the entering into permanent care by their family member was an extremely emotive, although relatively smooth transition. Viewed and, to a certain extent, welcomed as an extension of the participants' caregiving role. This was based on the fact that these caregivers and their relative not only had positive experiences of previously accessing respite care, but also that the participants, through the provision of relevant information, were able to undertake forward planning. Lucy offered an example of her husband entering permanent care, having previously accessed respite services in the same care home. This had been a joint decision within the family which they were "*happy*" to undertake, given that the staff knew her husband. However, this choice was also coloured by her acknowledgement that caring for her husband at home was no longer possible and further amplified by his death only a few months later. However, Lucy

re-oriented her feelings of losing her role as primary caregiver and the decision which had been made, by offering a subjective view that she felt that her husband would have understood.

Nevertheless, the permanent residential care setting often differed from the respite care setting, which created further considerations by participants. This was undertaken with support from not only other family members, but also care workers to ensure appropriate choice. However, for other participants who had accessed respite services, the transition into permanent care by their relative was unanticipated and therefore unplanned. These examples often occurred after a crisis event relating to the health issues of the caregiver and in some cases, the progression of physical and cognitive losses being experienced by their relative as highlighted by Peacock, Hammond-Collins and Forbes, (2014). Even though the participants of PG1 and PG2 involved with this study expressed that they had anticipated and considered that their family member would, at some point, enter care on a permanent basis, the crisis event prompted experiential feelings of guilt in being unable to continue their caring role within their family home. This then necessitated a re-balancing between their *relationship-self* and *caregiver-self* in being able to re-orientation themselves within their landscape of care.

All of the participants whose family member had entered permanent care remained fully involved in the life of their relative. For spousal caregivers this often encompassed day-to-day visits, thus ensuring the maintenance of '*couplehood*' as defined by Hellström, Noland and Lundh (2007); Kaplan (2001). It was also a way in which participants expressed being able to be involved and to "*share"* their caregiving role with care staff. Patricia spoke about her attempts to maintain her relationship with her husband, who had entered a care home on a respite basis after a crisis event related to her ill-health. However, this had subsequently developed into an unplanned permanent position, which Patricia felt extremely guilty about. This was further intensified by not only her concerns, but also those expressed by her friends, that the care being provided to her husband was insufficient. Yet, as with many of the participants she felt confident in her relationship with care staff to discuss her concerns.

Other participants also spoke about their struggle of living in "*two worlds*", the care home world and the world outside of this environment, as highlighted by Hennings, Froggatt and Payne (2015).

Caregivers also looked to the future during this point of their journey, anticipating the further losses to be experienced by themselves and also their relative, often brought about by incidents relating the physical fragility of their family member. In June's case this was associated with her anxiety that her husband wasn't receiving sufficient food, which prompted her to become increasing more involved with the care home. Yet, for June, it was also the realisation that her husband's health was deteriorating and her anticipation that they were together moving on to the next stage, the palliative care stage of their journey with dementia.

5.1.4 The Self at the End of the Journey and Beyond

This research study was not intended to be undertaken as a comparative study; however, the palliative care and end of life periods were reviewed by both groups of participants from two different perceptual horizons. Previously experienced in the near past by members of PG1, in contrast to an experience anticipated as occurring in the near future by members of PG2. For some members of PG1, who retrospectively referred to the palliative care period as being a significant experience, the time spent within this period was perceived by them as lasting between three weeks to two months. Yet the overwhelming experiential factor related to the environment in which the palliative and end of life of their family member had occurred. Although for several of the spousal caregivers, the palliative care period was not a definitive experience, but seen as being part of "*the long road"* of caregiving when their family member had either remained at home, or had entered a permanent residential care setting or hospice. That was until their dementia journey had ended with the death of their partner, due to either an additional health condition emerging, or the reoccurrence of other health-related issues.

During the exploration of their individual journeys the participants of both groups spoke of previously anticipating the final loss of their relative. They metaphorically projected themselves forward to future horizons in contemplating the final end of their caregiving experience. This was often considered within the context of having anticipated the remaining trajectory of their journey, as well as their anxiety as to whether they would be able to sustain their caregiving role into the future. In response to various aspects of their caregiving journey they echoed the ambiguity of dementia care, highlighting their experiences of the '*goodbye without leaving'* as emphasised by

Boss (1999). However, for some members of PG1 who had experienced the anticipated or sudden death of their relative, this manifested expressions of their family member *'leaving'* without affording them the opportunity to say '*goodbye*'. Although these participants, such as Susan, engaged in orientating and restoring their perception of *'loss'* as being the final expression of love by their spousal partner in shielding them from this event.

For some interview members of PG1, the palliative care and end of life periods had occurred within the family home. However, Brian was the only caregiving participant who spoke of the application of the Liverpool Care Pathway (LCP) within this environment. He reflected that this enabled a system of support to be established. Nevertheless, he appeared to have very little knowledge with regard to the process of the pathway and stated that the decision to cease the feeding of his wife via nasogastric intubation (NGI) had been made by medical care staff. Although unlike the findings of the independent study by Neuberger et al. (DH, 2013), he did not appear to see this as a lack of guidance by clinicians, but perceived that this system had given him the opportunity to care for his wife at home, during the final weeks of her life.

The LCP was also mentioned, but was not experienced as part of their caregiving role, by three spousal members of PG1, *"the carer support group girls"*; Molly, Sheila and Lucy. They spoke about information being offered at an Alzheimer's Society meeting by a solicitor and a branch care worker. Molly was the only participant who highlighted that this information was beneficial in emphasising the practical "*things*" that relatives, caring for a family member, could do and be involved with in planning for the future. However, she added a reflection that it did not assist in addressing the experience of the emotional issues of caregiving. This concurs with the findings of the international Delphi study undertaken by van der Steen and colleagues (2013; 2016), who report that psychosocial support is one of the lowest priorities of palliative care. However, the provision of psychological, social and spiritual support, highlighted as being of paramount importance by the NCPC (2006), were either not considered, or were only experienced by a limited number of participants within the palliative care and end of life stages of their journey.

These aspects of support were often sought and received from other people, such as other caregivers, family members and in some cases, by those who had expressed religious affiliations.

The full understanding of the goal of palliative care by all study participants did not resonate with the NCPC definition, as being "*the active holistic care of patients with advanced progressive illness*" NCPC (2006, n.d.). It appeared to be viewed from a medicalised perspective, relating to pain management and NGI intubation.

George highlighted this in his reflection of his wife entering permanent care and the assistance he then received from care staff in planning for the future. Although this was not the experience of the majority of the members of PG1, whose spousal partner had died within a care home setting. Yet, George's experience of not receiving relevant and timely information at the beginning of his journey was also replicated at the end of his caregiving role. He spoke of how he would have "*loved*" for the last few days of his wife's life to have been experienced within the family home, perceiving that she too would have wanted this to happen. Nevertheless, post-death he felt that she had, metaphorically, returned home in his expression of feeling her '*presences*' within his internal world. This sentiment was echoed many times by all of the participants involved with study group one, resonating with the research of Klass, Silverman and Nickman, (1996); Klass and Walter, (2001) as being the continuation of the bonds of attachment with the bereaved person. This was further augmented in the post-death ritual of '*speaking'* with their family member, which was often undertaken on a daily basis, regardless of if they had been with, or had not been with their relative at the end of their physical life.

For the four members of PG2, who were currently caring for their family member at home, palliative care was anticipated as being undertaken in the future, but was considered to be an integral and extended part of *"the long road"* of care. Palliative pathways of care were not mentioned, but participants did acknowledge the possibility of an increase in support services being provided by health and local authority care workers. The focus of these participants related to the future horizon and the physical end of life aspects of their caregiving role. For some, future planning had to be undertaken, with many referencing ACP, but again their knowledge relating to forward planning of care appeared to be limited.

For the majority of the members of PG2, their approach to forward planning was expressed in their wishes of being with their relative at '*the end'* and their related anxieties as to whether this would

be achieved. However, for the participants who did not engage in the seeking and application of ACP was not interpreted as a "*live for today, tomorrow you die"* philosophy to life attitude, as previously reported by Samsi and Manthorpe, (2011: 54). It again related to the lack of provision of relevant and timely information being offered and a failure of priority objective (4) in addressing improved end of life care for people with dementia, identified by the North of England Mental Health Development Unit (NEMHDU, 2015).

Members of PG2, whose relative is currently living in a permanent residential care environment, spoke about two perspectives associated with the palliative care period, which they perceive as being inter-related to the end of life of their spousal partner or parent. Some of the participants highlighted *'pin-point'* incidents which prompted their realisation of change relating to their relative's physical and cognitive health. Changes were associated with the behaviour of their family member, the necessity of assistance with eating and overall physical deterioration. This latter aspect specifically related to their lack of mobility. For other participants, these changes were less significant and were viewed through the lens of ambiguity. Marie offered her concerns regarding her mother's weight loss and lack of interest in food. She then went on to say that she was unsure as to whether this was a "*glitch*" in her mother's health and whether this was the beginning of the final stage and progression to the end of her caregiving journey. Only one participant member of this group, Harry, considered the end of his journey by proxy representation through Lindi, the family's elderly poodle. He reflected very early on in our first of three interviews, that once his wife Kathy had forgotten Lindi and vice versa, then he knew that it was the end.

With regard to the funeral arrangements relating to the cared-for-person, the majority of members of PG1 spoke about how they had pre-planned these arrangements with family members. This included the traditional rituals of the funeral service such as hymns and flowers. Spousal members of this group also spoke of reorienting their sense of self post-bereavement and how they perceived this could or could not be achieved. Only a small minority of spousal members of PG2 spoke about the funeral arrangements of their family member. This was interpreted as perhaps being too painful a subject for participants in anticipating the end of their schemas of *relationship-self* and *caregiving-self* vis-à-vis their husband or wife. Nevertheless, a small number of spousal participants of both groups did express their expectations relating to their '*reclaiming of self'* post-

bereavement, as highlighted in the previous study by Peacock et al. (2016). The perception of reclaiming their sense of self by some members of PG1 and PG2 was undertaken in the pursuit of activities throughout the latter periods of their caregiving journey. In addition, older spousal caregivers in particular spoke about their anxiety as to their own mortality. Only one participant involved with the research study, Jessie, expressed apprehension concerning the progression to the end of her own life would involve experiencing dementia herself.

5.3 Review of Chapter Five

This chapter has discussed the consistent themes of the physical and emotive experiences of family caregivers, as previously highlighted in dementia related research. In doing so it has addressed the aim of this research study in collectively exploring the experiences of a convenience sample of thirty family caregivers, involved in two non-comparative participant groups. The exploration of the caregiving journey undertaken by the individual members of PG1 was explored retrospectively to illicit an understanding of the experiences of bereaved family caregivers. In addition, the retrospective and prospective experiential accounts of individual members of PG2, who are currently caring for a family member with an advanced-stage experience of dementia, were also explored.

The participants involved with this study were twenty-six male and female spousal caregivers, as well as two caregiving dyads, comprising of male spousal caregivers and their respective adult-caregiving daughters. During the exploration of the individual journeys of all of the participants this study reflected on their caregiving experiences, highlighting the emergence of a conceptual and interpretative framework relating to the fluctuating schematic perceptions of self within a complex and tri-dimensional landscape. The fluctuating schematic representations of *me-self*, *relationship-self* and *caregiving-self* experienced by family caregivers, reveals their negotiation of their experiential perceptions of change, grief, loss and bereavement across the entire caregiving journey. The fluctuation of the concept of the schematic representations of self relating to family caregivers has not, to date, been reflected in other literature.

There were similarities between the experiences of caregiving expressed by members of both groups PG1 and PG2; the retrospective view of bereaved caregivers having reached the end of their

caregiving role and current caregivers who are currently continuing to care for their spousal partner or parent. Each described various periods of a complex and ambiguous journey, particularly relating to a protracted middle period defined as being "*the long road*" of caregiving. Given their stage-experience of caregiving there were also differential experiences expressed by participants associated with the latter stages of their journey. However, the overwhelming distinction related to gender and the way in which male and female participants negotiated and emotionally responded to change and experiential loss during particular stages of caregiving.

The majority of the female participants, who were able to actively seek a diagnosis of dementia with and on behalf of their spousal partner or parent, accepted their new schema of *caregiving-self*. Yet several participants chose to initially undertake this role independently, without the support from family members or care workers. In contrast, older male caregivers, with the exception of Bob and Harry who were part of the father and daughter caregiving dyads involved with this study, expressed that they were not offered a choice. They reported that they often experienced a lack of information at the beginning and also during various stages of their journey of care. Nevertheless, as with all participants, they accepted, albeit reluctantly, the subsequent change of their schematic representation of *relationship-self* and emergent acquisition of their role of caregiver.

Other gender-related differences highlighted the way in which participants negotiated and were able to undertake personal activities and to have *"me-time*" away from the challenges of their caregiving role, particularly during the latter periods of their journey. Only female spousal participants reported that they engaged in activities which were undertaken independently within the family home, or with their spousal partner, other family members, and other caregivers external to the family environment. The two adult-caregiving daughters did not refer to activities which had previously or were currently being undertaken. Their overall schematic representation of self by these participants related to their previous, current and anticipated caregiving roles.

As with the female participants, some male participants also actively sought more mindful pursuits of "*being in the moment*", which were undertaken within the family home. They perceived these activities as enabling them to pursue *"me-time"* and maintaining their schema of *relationship-self* with their spousal partner, whilst continuing with their day-to-day role of caregiving. Other male

participants engaged in joint activities with their spousal partner, whilst others reported their enjoyment of individual activities which were independent of their caregiving role. However, they acknowledged that independent activities undertaken outside of the family home could only be achieved with the support of family members or care staff. Nonetheless, both male and female participants considered that activities were an integral part of enabling them to maintain their schematic representations of *me-self, relationship-self* and *caregiving-self.*

The next chapter, the final chapter of this thesis, is a review of the aim of this study, discussing the format and methodical approach undertaken in carrying out this research. I also offer a reflective view with regard to my unanticipated parallel journey with participants and how this both challenged and assisted in my interpretation of their caregiving experiences. In addition, I highlight the limitations of this study, as well as the contribution to knowledge and aspects of the dissemination. In reflecting on the findings of this study I also consider recommendations for future research topics which have not been fully addressed by this research study. Finally, I offer a concluding statement.

Chapter Six: Looking Back and Looking Forward

6.0 Introduction

> At the beginning of this record I tried to explore the nature of journeys, how they are things in themselves, each one an individual and no two alike (Steinbeck, 1962: 208).

I felt that in this final chapter I should return to Steinbeck given that I considered him, at least in part, as being my "*literary cartographer"*. He was with me at the beginning of this research journey, therefore it seemed only appropriate that he be with me as I concluded this study. I concur, at least in part, with Steinbeck's final reflection in his comparative description of the nature of journeys as being individual and unique. The dementia caregiving journey undertaken by the participants of this research study involved an exploration of their individual journeys and, for some, clearly defined pathways of care. Nevertheless, there were some distinct similarities as to the way in which these family caregivers, in caring for their relative, began and continued to manage their caregiving journey in relation to their experiences of change, grief, loss and bereavement.

As the title of this chapter suggests, I offer a dual-horizon approach in reviewing and discussing the central aspects of this research study. Looking back, I begin by offering an overview of the format of this document, as well as a repetition and discussion of the aim of this study and the way in which this research aim has been addressed. Moving on from this, I review the methodological route undertaken and my reasons for applying a hermeneutical phenomenological interpretative approach to the data, extrapolated from the forty-eight interviews undertaken with the thirty participants involved with this study. I also discuss the application of additional data, particularly relating to entries in my reflective diary during the course of this study.

Looking forward I then discuss the limitations of this research study, as well as the contribution to knowledge. In addition, I outline previous and future dissemination of the findings. I also suggest recommendations for future research topics which have not been fully addressed in this study. Finally, I offer a concluding statement which is a reflection of the entire caregiving and research journey.

6.1. Reviewing the Format and Aim of the Research Journey

This thesis is divided into six chapters. Although chapter titles have purposefully deviated from the normative *'literature review', 'results'* and '*discussion*', I have been cognisant of ensuring clarity in documenting the step-by-step approach of this research study. From the very beginning I explore and discuss the landscape of dementia care from within the context of a journey. The reasons for this were deliberate and two-fold. Firstly, the journey metaphor is used in everyday common parlance and is easily interpreted as denoting our experiential perspectives. We all, at some point, during the course of our day-to-day lives refer to the undertaking of journeys, whether they have been undertaken physically or cognitively. Secondly, researchers such as Davis (2011); Fetherstonhaugh et al. (2017); Gillies (2011); Peacock, Hammond-Collins and Forbes, (2014); Teel and Carson (2003) suggest that within the context of the various stages and periods of dementia care, family caregivers also refer to their *'journey'* as a way to express their experiential perspectives.

I realised very early on in my examination of dementia related literature, which was synthesised and reviewed in chapter two of this document, that there is a paucity of research which has previously been undertaken, particularly relating to the aspects of change, grief, loss and bereavement across the entire dementia caregiving journey. This echoes the concluding comments of a study, as previously discussed, involving eleven bereaved participants undertaken by Peacock, Hammond-Collins and Forbes (2014), which highlight that:

> To the best of our knowledge, this is the first study to present the overall dementia caregiving journey from the perspective of bereaved caregivers (ibid: 9).

However, the aim of this research study undertaken by myself and also within the parameters of a journey relates to:

> the exploration, in part retrospectively, of the complex and emotional aspects of the fluctuating perceptions of self experienced by thirty family caregivers in response to change, grief, loss and bereavement during their entire dementia caregiving journey.

In addressing this aim, I have discussed the overall theoretical framework which underpins this study, as well as the emergence of the schematic concept relating to the fluctuating schemas of self embedded within a tri-dimensional landscape of dementia care.

In structuring this study, I found the adaption of symbolically stretching the theoretical framework of anticipatory grief, as previously outlined by Fulton and Fulton (1971) and Fulton and Gottesman (1980), across the entire landscape of dementia care, to be extremely beneficial. Adapting and utilising this theoretical framework is presented in chapter four of this document, and is interpreted as being a heuristic and stratified tri-dimensional-découpage representation comprising the: *topographical landscape*, *communicative landscape* and the *orientation of self and being within the landscape of dementia care*. Embedded in this tri-dimensional landscape were the stages and thematic experiences relating to the retrospective, current and anticipated experiences of members of both study groups.

The expansive and foundational landscape, the *topographical landscape* outlined in chapter four, section 4.1, served as a tapestried backdrop in exploring the complex and physical breadth of the caregiving terrain. Highlighting and addressing not only the retrospective, but also the current experiential perspectives of members of both study groups. However, the existential reality of the participants also emphasises the temporal dimensions of past, present and future in unison. Their perceptions of being within their caregiving-world resonated with the concept of the temporality of time, as suggested by van Manen (1990). Within our interview conversations participants continuously oscillated between the stages of their journey; often speeding up, then slowing down and also returning to specific stages to clarify their emotional responses to previous, current and anticipated future events.

In addition to the *topographical landscape*, the second and third landscapes offered a further thematically stratified approach to the presentation of data. Building on the foundational caregiving terrain described in the *topographical landscape*, the second landscape, the *communicative landscape* discussed in chapter four, section 4.2 of this document, encompasses a dialogical strata and additional thematic perspective of caregiving. This enabled the exploration of interpersonal aspects relating to the pivotal communicative experiences of participants during various stages of

their journey. Within this landscape participants reflected on the emotive conversations they had experienced with their cared-for family member, other family members, care workers and clinicians. They also highlighted their attempts in maintaining a sense of "*connectedness*" with their cared-for family member; as well as spiritual discussions and prayers with God. In addition participants also spoke of their internalised dialogues which they had undertaken in response to specific events. During the interview process participants offered many '*voices*' and experiences of unspoken aspects of communication, which often echoed the subtle nuances of these dialogues in character to clarify their experiences of different expectations and outcomes.

The third stratified layer offers the thematic *orientation of self and being within the landscape of care*, and is presented in chapter four, section 4.3 of this document. It outlines a representation of the strategies undertaken by both male and female caregivers, in their attempts to re-orientate themselves during the latter periods of their caregiving journey. These acts of re-orientation also related to experiential losses, both physically and cognitively, in relation to their family member during these periods.

Intersecting with this tri-dimensional landscape the analysis of data, undertaken in chapter three, reveals the central aspect of this study. The emergence of a conceptual framework involving three interconnected yet fluctuating schemas of self experienced by participants. The schemas of self interpreted as being *me-self, relationship-self* and *caregiving-self* were discussed and a diagrammatical representation (please see figure 5) was highlighted in chapter three, section 3.5.3. Although unlike the foundational *me-self*, the latter two senses of self, the *relationship-self* and *caregiving-self*, were afforded interpretative precedence by caregivers during the course of our exploratory conversations. From this schematic description of the interpretation of the fluctuating schematic perceptions of self and being within the landscape were highlighted (please see figure 6, section 3.5.3) with accompanying quotations offered by participants in chapter four of this document.

Further discussion outlining the similarities and differences to previous dementia related research and the findings of this study are presented in chapter five. As previously highlighted in the review of existing literature, I found that the concept of self in dementia related research has expansively

been addressed with regard to the person with dementia. However, with the exception of research undertaken by Sabat (2010); Peacock et al. (2016); Skaalvik et al., (2016) there still remains a scarcity of research which has been undertaken from the experiential perspective of self relating to dementia caregivers. This study has not only augmented previous research, but has also encompassed the entire dementia caregiving experience.

Given that I was aware of the emotive aspects of this research topic, I also found the application of the work of Rando (1986, 1988, 2000) to be immensely helpful in the interpretation of the theoretical perspectives of anticipatory grief and mourning in relation to the experiences reported by participants. Equally, the research outlined by Boss (1999, 2006, 2011) expanded my research and work-based practice understanding of ambiguous loss and dementia-specific grief. Nevertheless, it was the grief research work undertaken by Kübler-Ross (1970, 2009) and Kübler-Ross and Kessler (2005), relating to their definition and exploration of the five emotional stages of grief, which proved to be an extremely beneficial reference during data analysis. The five stage framework relating to the *'grief tools'* of emotion being acceptance; anger; bargaining; denial and depression.

As previously discussed, the work of Kübler-Ross (1970) and Kübler-Ross and Kessler (2005) emphasises that these stages are not *'stops'* on some linear journey and are not undertaken in any sequential or prescribed order. This was also reflected in this research study, as participants highlighted the application and re-application of these '*grief tools'* to varying degrees of intensity at different stages. However, throughout the interview and subsequent interpretation of the data process, it became apparent to me that the participants also expressed additional subterraneous emotions, which permeated throughout their caregiving landscape. An overwhelmingly positive aspect related to their continued expressions of love, particularly in attempting to maintain their bonds of attachment with their cared-for-relative.

Overwhelmingly, study participants repeatedly articulated their acceptance, albeit reluctantly, of having to continuously sever and retie their bond of attachment with their family member, which they expressed as assisting them to re-adjust to their experiential losses of caregiving. They expressed positive feelings of love, empathy and connectedness, in contrast to some participants

who also reported a negative aspect appertaining to their persistent feelings of guilt. Again this was predominately associated with their bonds of attachment with the cared-for-person, but also related to their locus of control. Participants of both groups also expressed their perceptions of being unable to cope in response to specific events and their anxiety of not being able to continue with their caregiving role. Essentially, this was predicated on their perceived lack of knowledge and receipt of information relating to and caring for their relative during particular stages of their caregiving journey.

6.2 Reviewing the Methodological Route

I began chapter three of this document by considering several reflexive questions relating to what would be my '*starting point'* and how I would actually commence this research journey. I had already clarified my research aim, but needed to consider which methodological and theoretical route I should undertake in order to elucidate robust and meaningful data. Metaphorically projecting my thoughts forward, I then considered what my research "*would", "could"* and *"should*" entail. Finally, anticipating what would perhaps be my journey's end.

As highlighted in chapter one of this document I had previously, for my MSc dissertation, undertaken a similar study although on a much smaller scale and had utilised a hermeneutic phenomenological interpretational approach. However, I felt that in undertaking this research study a more in-depth reflection should perhaps be given to other methodological routes, to ensure clarity and appropriateness. In doing so I entered into what can only be described as a methodological cul-de-sac in my review of other qualitative routes. Finally, a few weeks later, I emerged from this detour only to find that I had arrived back where I had initially started: at hermeneutic phenomenology. Nevertheless, I found this process to be extremely advantageous in not only highlighting the various aspects of the research process, but also in enabling me to revisit and review the philosophical work of Heidegger (1962), and especially Gadamer (1960; 1989; 1997; 1998).

Initially, this exploration offered the opportunity for me to consider practice implications to be implemented during the interview process and subsequently the analysis of generated data. Primarily regarding the three-fold format of my fore-structures of understanding, being the

acknowledgement of [my] prejudices or pre-understanding, which as Heidegger (1962) argues, are the necessary prerequisite conditions in relation to the interpretation of experience. This prompted the consideration and subsequent application during the interview process of the three essential qualities of counselling relating to congruence, unconditional positive regard and understanding, as highlighted by Sutton and Stewart (2008).

Returning to a hermeneutical phenomenological approach also assisted in enabling me to focus on the epistemological and ontological perspectives of the concepts self and being, as discussed in chapter five of this document. However, I had forgotten how impenetrable the work of Heidegger can sometimes be. So to further clarify my understanding of these concepts, I undertook a detour to review other literature, drawn from various interdisciplinary perspectives with regard to the concepts of self and being. In doing so I attained a deeper understanding, explicitly in reading the psychotherapeutic work of Sills (2009), which I was then able to utilise in my re-reading and further conceptualisation of the work of Heidegger and Gadamer.

My decision to use a hermeneutic phenomenology approach, explicitly a Gadamerian approach, enabled the transcendence of the boundaries between textual, spoken and indeed unspoken language in my analysis of the research data. The work of Gadamer (1989), as discussed in chapter three of this thesis, defines hermeneutical understanding as the mediation of two conjoined poles, a process of a *'fusion of horizons'*. Applying this process enabled participants and I to participate in mediating an exploration of their past and present experiences. Crotty (2015) offers a further hermeneutic interpretation of the fusion of horizons, suggesting that this is a centrifugal expansion of understanding, with the continuous movement of interpretation from the whole to the part and returning to the whole. This resonated with the illumination of the perpetual oscillation of the caregiving experiences expressed by participants. Applying this interpretative perspective during the data analysis process enabled an enhancement of the holistic depiction of their '*lived-world'*, not only in the past and present, but also in their anticipation of future experiences.

With regard to exploring the experiences of family caregivers, the dementia care landscape was familiar to me. The words I used in describing the commencement of this research study were my anticipation that I was not going to be a "*stranger in this land"*. From my work-based experience

this was certainly true. Nevertheless, I knew that the subject of this study was an extremely emotive topic, which necessitated robust inclusion and exclusion criteria in relation to participants to be involved with the research study.

Therefore, the preparation and *'mapping out'* of this study involved five Alzheimer's Society colleagues, who agreed to take part in acting as gatekeepers in the recruitment of potential participants. The predominant reasons for this being that they were in a unique position of knowing family caregivers who were not only still involved with their branch, but who would also be emotionally at ease with being interviewed. I had anticipated that this was going to be a rather convoluted recruitment process, which could have lasted for many months. Although in reality it proved to be a quick and successful approach in obtaining an appropriate convenience sample. All of the thirty participants involved with this study were recruited within a three month period, enabling the scheduling of one-off interviews for members of PG1 and the first interviews with members of PG2, being undertaken simultaneously.

On reflection the recruitment and interviewing of participant members of both study groups, during this initial period of data collection, should not have been undertaken in tandem. Even though this study was not a comparative study and the subsequent generation of data was brought together and collectively analysed, I believe that administratively I made more work for myself. However, I attribute this to my enthusiasm in "*wanting to get started*" and echoing Denzin and Lincoln's (2000) definition of the researcher as being the '*passionate participant*' within the phenomenological research relationship.

As I had envisaged, participants acknowledged a clear delineation between my Alzheimer's Society employee and researcher roles. This was attributed to a combination of the recruitment information documentation initially provided by myself, and further clarified by my Alzheimer's Society colleagues. Also, the pre-interview repetition of the purpose of the research study, during the pre-interview discussion and the signing of the declaration to consent to collect data from both the participants and myself, assisted in augmenting and defining my position.

However, there were occasions pre-interview when each of the caregivers engaged in Alzheimer's Society chit-chat, such as: *"did I know this person?*" or "*that person*?" I interpreted this as a way

for participants to ask reciprocal questions, thus enabling them to feel at ease and ensuring that they felt that they were an equal partner in the co-directing of our conversations. I also found the application of using my counselling skills to be helpful, particularly as the content of the majority of the interviews with study participants involved their repetition of extremely emotive and personal experiences.

Although, there were several incidents during the data collection and analysis periods which I found to be challenging, which were subsequently documented in my reflective diary. In particular, this related to the reported experiences of the two adult-caregiving daughters, Joyce and Marie, and the emergence of an unanticipated and perceived view of their *life-world* experiences which I felt paralleled my own reality during these periods. This aspect of my own experience was further intensified prior to the second interview with Rachael, who having read my father's obituary in the regional newspaper, empathically asked me personal questions about "*my*" dementia caregiving role. This illuminated an aspect of my life which, up until that point, I had not really considered or acknowledged. I found myself at a point of liminality, as Blandin and Pepin (2015) argue in their dementia-related research, as being a state betwixt a previously perceived position and moving forward towards an emerging situation. My perception of my sense of self changed. As with other fieldnotes relating to each interview, this incident was also included in my reflective diary and considered during the analysis process.

Early on in the analysis of data, with the initial reading of transcripts and reviewing of my fieldnotes, I was cognisant of two aspects. Firstly, the development of the stages of the caregiving landscape experienced by the participants. The second aspect related to the emergence of the schematic representation of self and the fluctuation of participants' perceptions of their self-schema, experienced during their entire caregiving journey. As previously stated, the participants highlighted complex experiential events and emotive responses throughout their journey, yet these stages often appeared to fuse together.

However, what I found to be the most revealing aspect was that certain stages of participants' individual journeys, such as "*the long road"* period, were cited more expansively than others. I had anticipated that the pre-interview information given to participants, highlighting that the study was

an exploration of grief and loss during their caregiving journey would generate a polarised perspective. Interpreted and weighted more at the beginning with the diagnosis of dementia, and at the palliative and end of life stages towards the end of their journey. Yet all of the participants offered a fulcrum based perspective, citing *"the long road"* period as being the most challenging in terms of their previous and current experiences of change, grief and loss.

6.3 The Limitations of this Study and the Contribution to Knowledge

> Physical death of a person with dementia is an important part of the experience of the journey for family members. The nature of the death may colour how the whole journey is then regarded in retrospect (Small, Froggatt and Downs, 2007: 35)

All studies have their limitations and I would like to state that this study is by no means an exception to that rule. However, I would also venture to suggest that perhaps the limitations also contribute to the strengths of this research. Within this section I begin with a personal perspective and then a practice-based viewpoint. Finally, I offer the contribution to knowledge in undertaking this research study and the dissemination of findings which have been undertaken. This research study has the limitation of many qualitative studies, given that it is based on a number of self-selected participants from one geographical area. A further limitation is that only family caregivers who could converse in English participated and therefore it cannot be said that the experiences that they expressed are necessarily representative of all family caregivers of people with dementia.

When I commenced this study I felt that I had a comprehensive pre-understanding of the experiences of caregivers, caring for a family member with dementia. As previously stated, the landscape of dementia care was not unknown to me. What was previously unknown to me was my own landscape of dementia care, which inadvertently paralleled parts of this research study. As discussed in chapter three of this document, Doucet (2008) highlights that the communities to which we belong are permeated by not only our assumptions relating to theoretical, epistemological and ontological understanding, but also by the possession of our personal conceptions which may have subtle or explicit outcomes. In quoting Small and colleagues (2007), I wish to acknowledge that my subjective experience may have contributed to subtle outcomes in the reporting of the knowledge collated whilst carrying out this research study.

However, I would like to offer a counterargument, that from the very beginning of commencing this research study, I was cognisant in recognising myself as being part of the *'skill-tools'* of research in my methodological approach and continuously sought to be both reflective and reflexive. In doing so I would suggest that my personal experiences of dementia care, although extremely emotive in the past and still at times permeating through my memories and filtering into the present, have nonetheless assisted in my holistic interpretation of the experiences of participants involved in this study.

From a practical-based viewpoint, this study was carried out with a convenience sample of caregivers who were still involved with Alzheimer's Society branches within the North East region of England. Although many referred to their pathways of care as initially being difficult, especially associated with the non-provision of information at various stages of their journey; their subsequent experiences of practical support from the Alzheimer's Society were extremely positive. This leads to the question as to possible research to be undertaken with family caregivers who have not, or have been unable to access support from services offered by the Alzheimer's Society or other voluntary sector organisations. For example, all of the participants involved in this study were of white British origin and caring for either a spousal partner or parent. Caregivers who were not represented were from lesbian, gay, bisexual and transgender (LGBT) groups, or members of black and minority ethnic (BME) groups. My anticipated inclusion of caregivers from LGBT groups, and in particular the BME community was not realised, due to the non-participation of one Alzheimer's Society branch based within a large urban area, as previously discussed in chapter three of this document. Thereby, I acknowledge that the contribution to knowledge of this study is limited with regard to the dementia caregiving experiences of members of other cultural groups. In addition, the role undertaken by close friends of the person with dementia, who may often be considered as '*members of the family'*, yet who perhaps feel that their experiences of self, change, grief and loss are disenfranchised and not, as Doka (1986, 2014) suggests, acknowledged by other family members was not realised.

Nevertheless, I argue that the contribution to knowledge of this study can now been viewed as addressing an expansion of the limited research previously undertaken relating to several features

of the entire dementia caregiving journey, of not only bereaved caregivers, but also those who were actively continuing their caregiving role.

From a theoretical perspective this study complements the limited knowledge relating to the experiences of self, change, grief, loss and bereavement of dementia caregivers from dementia diagnosis to final bereavement. In addition it has, in part, explored inter-family relationships with regard to the inter-relational experiences of father and adult-caregiving daughter dyads. Although I acknowledge that within the boundaries of this study, the experiences presented of dyadic relationships within the family has only allowed a skimming of the surface of the caregiving terrain. Overall, the central feature of this study has highlighted the emergence and opportunity to explore the schematic representation and fluctuating perceptions of self experienced by caregivers, which previously has not been fully addressed in dementia literature.

6.4 Dissemination of Research

It was my intention at the commencement of this study and as stated in the documentation for participants that everyone involved with this study would receive a summary of the research. However, my transfer from a full-time PhD studentship in 2012, to continuing my research on a part-time basis, increased the duration of this study. At this point my Alzheimer's Society colleagues were made aware of the format change and this information was cascaded to participants involved with this study. In addition, as highlighted in chapter three, section 3.6 of this thesis relating to the experiential events of my unanticipated research journey, has further extended the completion of my study. In doing so I am now aware that only one out of five of my former Alzheimer's Society colleagues involved at the beginning of this study, are still employed with the organisation. Two of out of the five Alzheimer's Society branches have ceased offering services and have subsequently closed. Also, given the passage of time I have been informed that many of the members of PG1, those who were bereaved family caregivers, are also no longer involved with the organisation and several participants have died.

With regard to members of PG2, who at the point of data collection were still actively caring for their family member, they are now bereaved and the remainder are no longer involved with their local branch. Nevertheless, a summary will be offered to the Alzheimer's Society at regional level.

Relating to grass roots implementation, it is my intention to contact the North of England Mental Health Development Unit (NEMHDU) to identify other areas of dissemination. Given that this research study resonates with the priority areas relating to dementia care in the North East of England identified by the NEMHDU report (2015) as discussed in chapter two of this document.

However, there are other avenues of dissemination which have been explored, undertaken and which will be pursued in the future. In 2015 I was contacted by someone I had the pleasure of working with several years ago and who is now an Admiral Nurse Professional and Practice Development Facilitator for Dementia UK. Subsequently, I have been commissioned to present my research and have facilitated three workshop events for thirty Admiral Nurses from the North West and North East regions of England in 2017 and 2018. Further workshops are scheduled to take place both in southern and central regions of England, as well as in Scotland in 2018. These workshops not only enable Admiral Nurses to explore working with people living with dementia, but also to address their own issues relating to possible parallel experiences of caring for members of their family who may have lived, or who are currently living with dementia.

In addition, I have also presented my research at four international conferences. A Pan-Pacific and South East Asian Dementia Care Conference, hosted by Chang Gung University and the Minister of Health, Taoyuan City, Taiwan (2015); the 6th International Carers Conference in Gothenburg, Sweden (2015); Life with Dementia Conference at Linköping University, Norrköping campus, Sweden (2016) and the Alzheimer's and Related Disorders Society of India, International Conference in Kolkata, India (2017). Also, it is my intention to pursue the publication of papers in peer-reviewed journals relating to this study, which will augment previous dissemination undertaken. I anticipate that at least one paper will relate to the findings of this research study appertaining to the experiences of family caregivers. A further paper will offer an auto-ethnographical perspective of dementia research paralleling my dementia caregiving reality.

6.5 Implications for Practice

The foundation of my understanding of dementia care is firmly based in supporting people living with dementia. As a former dementia care worker and now as an academic researcher and lecturer, my motivation in commencing this study was to further enhance knowledge relating to the sense of

self, change, loss and bereavement experienced by family caregivers during the entire dementia caregiving journey. The findings of this study have reinforced my perspective that the dementia caregiving journey is a unique experience, even if it is undertaken by members of the same family and impacts on the caregiver's individualised sense of self. Nevertheless, there are similarities between age and gender groups of family caregivers which still need to be addressed.

For example, the priority areas for the north east region identified by the *Living Well with Dementia, A Participation and Engagement Programme for People with Dementia and their Carers* Report (NEMHDU, 2015) highlight several objectives. With objective (2) being the need for good-quality early diagnosis and intervention. Several older male members of PG1 and PG2 of this research study spoke of their perceived lack of information and support not only at the beginning, but continuing throughout their caregiving journey. Whilst the majority of female caregivers of both participant groups reported experiences of easy access to care, support and advice following diagnosis, as outlined in objective (4) of the NEMHDU report.

Objective (5) of the NEMHDU (2015) report relating to the development and access of structured support was also reported by all members of PG1 and PG2 of this study as being addressed by staff of their local branch of the Alzheimer's Society. Although peer support was only received and undertaken by some participants who were able and who chose to become active members of structured groups, particularly during the protracted *"long road"* period of their journey.

In addition the majority of older male and female participants expressed a lack of knowledge, information and choice with regard to the provision of services especially relating to end of life care, (as outlined in objective (12) of the NEMHDU report). Overall participants involved with this research study did not cite their dementia caregiving experiences as being undertaken within a definitive pathway of care.

6.6 Recommendations for Practice and Future Research

The findings of this research study have highlighted the importance with regard to people living with dementia, especially family caregivers, receiving appropriate information and ongoing support. An outline of recommendations for practice and future research are outlined below.

6.6.1 Recommendations for Practice

a. The provision of clear and concise information being offered by healthcare staff in relation to the possible trajectory and potential experiences of the entire dementia care journey. This is especially important during the protracted middle period of the caregiving journey, described by participants of this research study as being "*the long road*" of their caregiving experience. However, it is predicated on the family caregiver(s) and the person with dementia wishing to receive this information at the point of diagnosis and beyond.

b. The introduction of targetted information, outreach support and peer group contact to address the needs of older caregivers, particularly male, living within rural communities.

c. This study has also highlighted that academic researchers, such as myself, should possess a greater awareness of their own schematic perceptions of self, whilst encountering the emotive issues in undertaking dementia care research. Especially if they are, or during the course of the research process they subsequently become a dementia caregiver to a member of their own family

6.6.2 Future Research

Even though the penultimate entry in my reflective diary, written over a year ago, candidly states that this research journey has been:

> "*an emotionally arduous process and even though I have always wanted to undertake research relating to anticipatory grief, loss and bereavement across the entire caregiving journey of experienced dementia caregivers, I don't see myself repeating this topic of research. Well, perhaps not in the immediate future".*

Nevertheless, I now feel able to reflect on potential topics relating to the dementia caregiving experience of family members which I believe require further examination. I offer these proposals as three topical sections:

Aspects of the Relationship-self and Caregiving-self within the Family

a. The concept of the schematic representations of self experienced by married couples in caring for a parent / parent-in-law: this research topic would explore the aspects and effects of caregiving within their own martial relationship.

b. Being in the moment, whilst looking to the future: this research topic would focus on the gender differentiated strategies employed by current family caregivers in maintaining their sense of self, whilst continuing to undertake their caregiving role.

c. Parallel reality: this topic of research would address the auto-ethnographical experiences of academics undertaking, or having undertaken dementia-related research whilst also being a caregiver to a family member living with dementia.

6.7 Review of Chapter Six

The final chapter of this document offers an overview of the format, methodological routes undertaken and theoretical frameworks applied to address the aim of this research study. I have discussed the emergence of the theoretical concept of the fluctuating schematic perceptions of self experienced by participants within their landscape of care. I have discussed the inclusion and contribution of notations in my reflective diary, which assisted in enabling me to interpret the data collated during the research process. The contribution to existing knowledge has also been indicated, as well as previous and future dissemination of the findings of this research study. In addition I have also highlighted that there are limitations to this study, but in addressing these limitations I also offer potential recommendations for practice and future research topics to be considered. Finally, I would like to offer my concluding statement to this study.

6.8 Conclusion

Looking back, this research journey has involved many people. Not only the study participants and myself, but during the course of our exploration of their individual landscape of care we were joined by and heard the *'voices'* of others, in particular, the cared-for-person, their husband, wife or parent. In addition, the experiences of other family members, care workers, poets and pets, as well

as academic researchers and philosophers. All of whom were brought together in the emergent interpretation of the fluctuating perceptions of self experienced by participants within an emotional and tri-dimensional landscape. From the very beginning participants emotively spoke of memories of love and their continual attempts to negotiate their fluctuating perceptions of self, change, grief, loss and bereavement, stretching back to past horizons and onwards into anticipated futures. This study has offered an exploration of journeys comprised of subtle differences, but overwhelming similarities of the experiences of caring for a family member with dementia. However, the unanticipated aspect of this research journey was my own parallel experiences of change, grief, loss and bereavement. I acknowledge that very early on in this research study I stated that I wanted to empathically *"touch"* and to emotionally *"feel"* the data. What transpired during the course of this research journey was my perception, at times, of being *"submerged"* within the landscape of dementia care not only with regard to the experiences of participants, but also in response to events in my own life.

The final notation within my reflective diary states:

> "*As with all of the participants involved with this study, my schematic representations of self have fluctuated. My sense of self has changed. Nevertheless, I can say that academically, professionally and now personally I am not a stranger in the dementia care landscape.*"

Finally, on reflection, as my father (Vasili Jacovitch Oleksuik) would have said, because he always liked to have *"the last word",* it is a journey which has been undertaken by:

"По довгій дорозі"
(po dovhiy dorozi)

"The Long Road"

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Appendices

Appendix 1.0: Studies describing the characteristics of dementia caregiving by family members

1.1 Review of literature undertaken in 2009

Author(s) / Year / Country, Journal Source: *(abbrv. given)*	**Study design/aim**	**Sample characteristics of participants**	**Main themes/findings**
Adams et al. (2004) US Dementia	Mixed-methods study to explore the self-reported losses, grief reactions and depressive symptoms of family caregivers.	Randomised selection of n=99 family caregivers involved with the Alzheimer's Association (north-eastern area of US. Mean age of caregiver 59.07 (28-89 years).	Findings suggest that caregivers experience different emotional tasks of grieving at each state of their caregiving experience.
Adams (2006) US J Gerontol Soc Work	A mixed-method analysis of the self-reported experiences of loss, grief and depression by caregivers caring for a family member with Alzheimer's disease.	n= 99 (30 male & 69 female) Mean age 59.07, age range 28-89 years. Ethnicity and other details not specified.	Different emotional tasks experienced by caregivers and the importance in acknowledging the loss and facilitation of grieving at each stage of the caregiving experience.
Adams et al. (2008) US Dementia.	A cross-sectional study, to examine primary subjective stressors experienced by family caregivers.	n=428 spousal caregivers, adult children and other family members. Age range 31-84 years. 63% female. Ethnicity: 83% white. Further details not specified.	Subjective stressors reported: -Loss of intimate exchange -Current quality of relationship -Loss of self and depression experienced by caregiver.
Arber & Ginn (1990) UK Ageing Soc.	Historical examination of sociological research and UK policy relating to the exclusion of the societal perception of older women.	N/A	Main findings: -Neglect of British sociology with regard to: -Resources and divisions with households -Family relationships and social stratification. Concluding that older women and men must become research subjects in their own right.

Author(s) / Year / Country of study, Journal Source: *(abbrv. given)*	**Study design/aim**	**Sample characteristics of participants**	**Main themes/findings**
Archer & MacLean (1993) UK J Gerontol Soc Work.	An examination of the experiences of husbands and sons as caregivers for chronically ill older female family members.	Qualitative study based on in-depth interviews with six male caregivers. Further details not specified.	Participants reported changes within their relationships and further strategies applied to enable them to continue to undertake their caregiving role.
Austrom & Hendrie (1990) US J Alzheimer & Related Disorders Res.	Exploration of the emotional experiences of family caregivers caring for a relative with dementia in comparison to caregivers caring for a family member with cancer.	n=244 – spousal and adult children n=47% female (29-85 years) n= 16% male (29-75 years of age) responding to a 47 item questionnaire.	Findings highlighted included the experience of: -Anticipatory grief -Denial of diagnosis which often lasted for several years -Depression and loss of social contact -Anger
Boss (2004) US J Marriage & Family.	An overview of three decades of research, theory development and clinical application relating to ambiguous loss. [This paper was written in the aftermath of 9/11]	Review of author's own work relating to the physical and psychological types of ambiguous loss.	The author concludes that research-based theory is essential to inform the development of interventions in unexpected times of terror and in everyday life.
Braun et al. (2009) US J Aging & Health	To explore previous research relating to the dyadic and relational variables of people with dementia and their spousal partners.	Literature review of studies addressing: -Perspective of the caregiver only -Caregiver and partial consideration of their cared-for partner -Perspectives of cared-for person and spouse.	The integration of the dyadic perspective of affected couples provides essential information for interventions.

Author(s) / Year / Country of study, Journal Source: ***(abbrv. given)***	**Study design/aim**	**Sample characteristics of participants**	**Main themes/findings**
Brodaty & Green (2002) Australia. Fam. Physician.	Article outlining the needs of family caregivers and the role undertaken by GP in the provision of support.	Topics highlighted aspects of caregivers' health and lifestyle which may be compromised: -Psychological -Physical -Social -Financial	To reduce adverse health effects experienced by the caregiver, GP has a key role and is a partner to caregivers in the provision of support and long term management of care.
Brodaty et al. (2005) Australia J of Geriatr Psychiatry.	To develop a typography of the characteristics of caregivers and cared-for family members and the non-use of services. Random sampling.	n=109 (5 below 35 years of age, 38 between 35-49, 33 between 50-64 and 33 reported as being 65 + years. 73.4% female 60% adult caregivers, and 36% spouse and 13% other.	A substantial need for a variety of services required to address: -Perceived lack of awareness of services available -Destigmatising dementia -Involvement of care practitioners.
Brodaty & Donkin (2009) Australia J Clin Neurosci.	An in-depth literature review to investigate both the positive and negative effects of family caregivers.	Topics include: -Global perspectives of caregivers and categories -The provision and types of care -Physical and psychological effects of caregiving -Services and interventions.	Discussion findings: Appropriate interventions required to address the negative factors of caregiving. Comprehensive planning required which involves clinicians, caregivers and the cared-for person.
Calasanti & Bowen (2006) US J Aging Std.	Qualitative study, in-depth interview data. Aim: To explore the way in which gender may influence spousal caregiving.	n=22 spousal caregivers. n=13 women (range, 53-78 years) n=9 male (range 65-83)	Male and female cross gender boundaries in performing caregiving tasks. Recognition of the other as a gendered being and the importance of masculinity or femininity to personal identity.

Author(s) / Year / Country of study, Journal Source: *(abbrv. given)*	**Study design/aim**	**Sample characteristics of participants**	**Main themes/findings**
Cascioli et al. (2008) UK Qual Ageing Older Adults	Qualitative study, to explore the demands and emotional strain associated with caring.	n=45 Ethnicity: white British Male carer to female carer ratio: 14:31 Spouse carer to adult child 24:21	Study revealed the need for improvement in -Communication -Information -Emotional support Particularly with regard to the caregivers relationship with social and healthcare services.
Chappell & Reid (2002) Canada J Gerontol.	Mixed methods study including structured face-to-face interviews to explore the experience of burden and well-being among caregivers.	n=294 Mean age of caregivers = 51.1 years. n=69.1 female Mean hours of informal care provided weekly was 26.1 hr within a range of 0-168.	Social support strongly indicated to the overall experiences of well-being of the caregiver, even with the experience of caregiver burden being present.
Cooper et al. (2008) UK J Geriatr Psychiatry.	A longitudinal study (mixed methods, including interviews and focussed coping intervention strategies). Aim: to explore the relationship of anxiety and coping strategies experienced and undertaken by caregivers.	n=93 Spousal caregivers n=59 female n=34 male. No other details specified.	Emotion-focussed strategies seemed to protect caregivers from developing higher anxiety levels. Whilst problem-focussed strategies did not.
Cooper et al. (2009) UK BMJ.	A mixed-methods study, to determine the prevalence of abusive behaviours by family caregivers of people with dementia.	n=220 family caregivers. Ethnicity: white British n=144 female n=76 male n=44% spousal caregivers n=56% caring for a parent.	Abusive behaviour by family caregivers towards the cared-for family member is common. One third of participants reported important levels of abuse. Although few cases of frequent physical abusive behaviour was not reported, possibly due to the reluctance of participants.

Author(s) / Year / Country of study, Journal Source: ***(abbrv. given)***	**Study design/aim**	**Sample characteristics of participants**	**Main themes/findings**
Crispi et al. (1997) US J. Gerontol.	Mixed-methods study to investigate the impact of attachment to a parent living with dementia residing within a care home environment experienced by adult child caregivers	n=61 female n=47 male Mean age: 55.8 Ethnicity: All Caucasian Religion: 24 Catholic, 20 Protestant, 56 Jewish and 6 other.	Adult children who had a high level of interaction and preoccupation with regard to their parent's care, experienced higher levels of distress. This was in contrast to adult children who had a lower level of preoccupation and interaction with their cared-for parent.
Daniels et al. (2007) US Fam Syst Health.	A qualitative single-case study exploring the marital relationship of one spouse diagnosed with Alzheimer's disease	Husband and wife (the cared-for person who had been diagnosed with AD five years earlier). Both participants were in their mid-80s. The couple lived within their own home. Further participant details not specified.	Emergent themes: -Perspectives and preparation of future changes -Family influence and support -Life evaluation -Experiences with AD
DiBartolo (2000) Japan J Gerontol Nurs.	A mixed-methods study including a General Health Questionnaire to further explore the prevalence of depression reported as occurring among 1 in 4 family caregivers.	n=95 n=61 female n=34 male. Age range of participants 38-87 years.	Identifying the underlying mechanism of the relationship between: -Development of poor mental health of caregiver -Associated caregiver burden and behavioural problems displayed by cared-for family member.
Downs et al (2006) UK J Palliat Nurs.	A description of explanatory models of dementia and links to palliative care and end-of-life experiences of people with dementia, family caregivers and practitioners.	Exploration of dementia as: -Neurological condition -Neuro-psychiatric condition -Normal part of ageing.	Findings: -Too little is done: requiring engagement with levels of resources/training of care staff and family members -Too much is done: by family members requiring use of imaginative responses to difficult problems.

Author(s) / Year / Country of study, Journal Source: *(abbrv. given)*	**Study design/aim**	**Sample characteristics of participants**	**Main themes/findings**
Ducharme et al. (2006) Canada J Nurs Stud.	Mixed-methods study to determine the factors associated with the primary and secondary health related stressors experienced by older husband caregivers.	n=323 mean age 73 years. Mean age of spousal partner 72 years. 46% of husbands had cared for their wife for 5+ years.	Findings indicate role overload linked to: -psychological distress and lower self-perceived health experienced by participants.
Farran et al. (2003) US Dementia	Semi structured interviews to examine spirituality of family caregivers	African/Latino and Caucasian) n=20 (actively caregiving) n=23 (bereaved caregivers or service providers) 84% of participants were female (30-89 years)	Four major findings: faith, the role of faith, benefits of spirituality and the care-receiver/caregivers experience. Implications for practice - community-based outreach approaches should embrace faith developments.
Fortinsky et al. (2002) US Dementia	Structured interviews to explore the intervention of an Alzheimer's coordinated service programme (ASCP Cleveland) for family caregivers.	n=62 87% were women, mean age 59 years (range = 26–84 years). Majority female adult caregiving children.	The provision of the ASCP service was indicated as having a positive impact, enabling care professionals to refer family caregivers to the programme at an early stage of their journey.
Furlong et al. (2008) Canada Qual. Health Res.	To explore the self-care needs of caregivers using a grounded theory approach.	n=9 Ethnicity: White English-speaking Canadian. n=6 Female n=3 Male Age range: 49-79. Further information not specified.	Caregivers lost sight of the importance of self-care and self-care worthiness. Older caregivers often relying on their spouses for external sources of self-care authentication. Recommendations for practice: services providers to include interpersonal communication techniques for caregivers.

Author(s) / Year / Country of study, Journal Source: *(abbrv. given)*	**Study design/aim**	**Sample characteristics of participants**	**Main themes/findings**
Gaugler et al. (2005) US Psychol Aging	Longitudinal study (3 years) part of which examines the change in burden and depression of family caregivers. One-to-one interviews.	n=804 participants. 74% = female. 40.8% spousal. Mean age= 60.	Need to consider experiences early in the dementia caregiving career and the importance of attrition when attempting to model the health implications of informal long-term care over time
Hellström et al. (2007) Sweden Dementia	A single case study exploring the flourishing of the relationship of one married couple living with dementia.	Semi structured interviews undertaken separately with n=2: husband and wife. Aged 86 and 83 years respectively.	Couplehood is an essential element in the experiences of married couples and their response to the impact of dementia.
Kaplan (2001) US Fam Relat.	Qualitative analysis of 68 community-dwelling spouses where partner resides in permanent residential care. Aim: to ascertain to what degrees of '*couplehood'* emerged.	n=68 spousal caregivers -n=42 female n=26 male Ethnicity=67 white. n=1 other With 50% visiting their spouse every day.	Themes highlighted: -'*Til Death Do Us Part'* -Husbandless Wife or wifeless husband -Becoming "*I* "– participants continuing with life -Unmarried married – no longer feeling a couple.
Nay (1995) Australia J Clinic Nurs.	In-depth interviews with nursing home residents and families to explore the lived-experienced of care.	19 Nursing home residents and family members. Further details not specified.	Themes provided the interpretation and subsequent understanding of the aspects of relocation into permanent residential care.
Netto et al. (2009) US Dementia	A qualitative grounded theory approach involving semi-structured interviews. To investigate the gains experienced by family caregivers in undertaking their role.	n=12n=10 female & n= 2 male Ethnicity: Chinese and Asian Indian Spousal and children	Findings reported a move from the burden of care, to the enriched experiences of caregivers and consideration towards a more holistic approach in assisting caregivers in their dementia caregiving journey.

Author(s) / Year / Country of study, Journal Source: *(abbrv. given)*	**Study design/aim**	**Sample characteristics of participants**	**Main themes/findings**
Nolan et al. (2002) UK Dementia	Comparable study of literature examining the development of academic research and person-centred model within dementia care practice.	Literature review, article selection process not specified.	Knowledge and understanding requiring a more empowering and inclusive model of research and practice. The development of a relationship-centred approach to care.
Norman et al. (2004) UK Dementia	Mixed-methods study To examine the nature of care where care was partly provided by their resident/non-resident family members or friends.	n=20n=9 spousal caregivers (4 husbands/5 wives) n=7 adult daughters (4 non-resident/3 resident) n=4 other relative/family member.	Perceived change and coping strategies: -Routines/practices -Deterioration of cared-for family member -Attempts to understand dementia and regain control.
O'Rouke & Tuokko (2000) Canada J App. Gerontol.	A mixed-methods study to examine demographic / illness outcomes experienced by caregivers.	n=181 patient. Caregivers: 83% female spouse or other family member. 17% male spouse or other.	Problematic outcomes of caregiving differ with regard to the affective experiences and physical health of the caregiver.
Paoletti (1999c) Italy J Women Aging	Qualitative study exploring the impact of caring on caregivers' life style and health. Interviews with women caregivers analysed through detailed discourse analysis.	n=3 female. Adult caregiving children each caring for their respective mothers. Ethnicity: Italian. No further details specified.	The importance as to the understanding of caring which can produce serious physical and psychological problems. Themes: -The stress of caring -Positive experiences of caring -Feelings of "*no way out"*
Paoletti (2001) Italy Human Stud.	A qualitative study (interviews analysed through discourse analysis) to examine the perceived gender specific practices of caregiving.	Interview data of 8 audio-recorded interviews (pilot study). Selected participant interviews discussed.	Themes and sub-themes related to: -Caring as a category-bound activity -Time appraisal and gender typifications -Distancing from caregiving as a feminine activity.

Author(s) / Year / Country of study, Journal Source: *(abbrv. given)*	**Study design/aim**	**Sample characteristics of participants**	**Main themes/findings**
Pinner & Bourman (2003) UK Adv Psychiat Treat	Review of literature to examine what clinicians should tell patients and carers about dementia.	n/a	Medical practitioners, relatives and carers appear more reluctant to disclose diagnostic information to patients with dementia.
Pringle (2003) Canada Can. J Nursing Res.	Discourse relating to making moments matter for family caregivers.	n/a	Exploration of quality of life issues for people living with dementia.
Robinson et al. (2009) Australia Dementia	A qualitative study to explore family caregivers' experiences in accessing dementia information and services in Southern Tasmania.	n=15: n= 5 male (n= 3 under 65 years caring for a parent, (n-2 aged between 66-85 years) caring for spouse=10 female (aged 56-65 years) caring.	Themes reflected participants' progressive care experiences with regard to seeking appropriate information: -Hurtful and dismissive -Futile searching -Resolution after delayed receipt of services.
Sanders (2008) US Death Studies	This study presents qualitative results from a mixed-methods descriptive study, exploring the lived-experience of family caregivers.	n=44. 86% female. Equally divided between spousal caregivers (n=23) and adult children (n=21).	Seven themes emerged: - yearning for the past - regret and guilt - isolation - restricted freedom - life stressors - systemic issues - coping strategies.
Shanley (2006) Australia. J Alzheimers Dis Other Demen.	Qualitative study exploring the flexibility and provision of respite services for people living with dementia.	Staff and volunteers from 26 day programmes and staff from 10 services providing multicultural dementia care. Breakdown of participant details not specified.	Findings included: -Respite care is highly valued by carers. -Flexibility required in addressing complex and individual needs of people living with dementia. -Development of a flexibility checklist for respite services providers.
Schultz & Martire (2004) US J Geriatri Psych.	A summary of literature, identifying key interventional caregiving approaches regarding practice guidelines..	Review of literature, process not specified.	Development of the stress/health model applied to caregiving and associated interventions.

Author(s) / Year / Country of study, Journal Source: *(abbrv. given)*	**Study design/aim**	**Sample characteristics of participants**	**Main themes/findings**
Schultz & Sherwood (2008) US Am J of Nurs.	A review of literature exploring the features of chronic stress experienced by family caregivers.	Review of quantitative and qualitative literature.	Indicated predictors of effects relating to physical and mental ill health. As well as positive aspects of caregiving experiences.
Smith & Kobayashi (2002) Japan Dementia	An appraisal of cultural values and life history events to gain a deeper understanding of the experiences of a Japanese Canadian family.	Single care study of Mr T (aged 82 years) his wife and family. No other demographic details specified.	Findings of this study suggest a need for a life-course approach in understanding the diverse responses to dementia from a familial and ethnic context.
Sweeting & Gilhooly (1997) UK Sociol Health & Illness	An exploratory qualitative study to examine the extent to which *'social death'* may occur before biological death experienced by people with dementia.	n=100 caregivers relatives of people Mean age 60 years (28-81) n=26 males n=74 female (spousal and divorced partners).	A range of issues relating to the concept of '*social death*' experienced by caregivers was indicated at varying degrees of intensity/experience.
Teel & Carson (2003) US J Fam. Nurs.	A qualitative (thematic) study to explore the experiences of families seeking diagnosis and subsequent care/treatment for a family member with dementia.	Semi-structured interview and questionnaire undertaken with 14 family caregivers. 64%=female Ethnicity –white. Age range 45-83. All but one was a spousal wife. Details of male participants not specified.	Themes identified: -Uncertain journey through diagnosis -Lonely journey through dementia care -Sharing lessons learned from caregiving In addition implications for future healthcare involvement were also indicated.
Treloar et al. (2009) UK Dementia	A mixed methods study, undertaken retrospectively with caregivers whose family member had died within a hospital setting, after previously being cared for at home.	n=14, (7 female and 7 male) 10 spousal 4=children. Mean age 68.1 – age range 36-91.	Study revealed blockages to accessing support and a poor understanding of the needs of advanced dementia care.

Author(s) / Year / Country of study, Journal Source: *(abbrv. given)*	**Study design/aim**	**Sample characteristics of participants**	**Main themes/findings**
Ward-Griffin et al. (2007) Canada J of Fam. Nurs.	Qualitative study to explore the relationships between adult daughters and their mothers with dementia. Guided by socialist-feminist theory and a life-course perspective.	n=10 community-dwelling mothers with mild to moderate cognitive impairment (mean age (mean age = 84.6) and n=15 caregiving daughters including sibling sisters (mean age 49.6).	Four dynamic types of mother-daughter relationships: -Custodial, combative, cooperative, and cohesive. - Custodial and cooperative relationships mainly focused on the provision of and receipt of tasks. -Combative and cohesive being emotion focused.

Appendix 1.0 Studies describing the characteristics of dementia caregiving by family members

1.2 Review of literature undertaken in 2016

(including further literature highlighted through e-journal alerts during 2016-2017)

Author(s) / Year / Country of study, Journal Source: ***(abbrv. given)***	**Study design/aim**	**Sample characteristics of participants**	**Main themes/findings**
Blandin & Pepin (2015) America Dementia	Literature review and discussion of theoretical models addressing therapeutic interventions relating to the process of grief experienced by dementia caregivers.	Review of international literature from 1990 – 2014. The process of the systematic review was not specified.	Emergent themes and sub-themes indicated an iterative grief process involving three dominant states: -Separation -Liminality -Re-emergence of self.
Caddell & Clare (2011) UK Dementia	Qualitative study applying an IPA approach. Aim: to explore participants' perceptions of the impact of dementia.	n=10 diagnosis of dementia n=5 male and n=5 female. Age range 65-88. Ethnicity: white European origin, born or had resided in the UK since childhood.	Participants appeared to be in a state of flux, experiencing both continuity and change relating to their sense of identity.
Chan et al. (2012) UK J Geriatr Psychiatry	A systematic review of research literature. Aim: to explore and discuss the complex reaction experienced by family caregivers relating to grief and loss in dementia care.	Sample of 31 publications were reviewed which met a predetermined criteria. n=17 quantative studies n=11 qualitative studies n=3 applying a mixed-methods approach.	Findings suggested that the experience of grief of family caregivers is expected. However, those at risk of experiencing the distressing aspects of anticipatory and complicated grief may be identified and targetted earlier with the establishment of appropriate intervention processes.
Clarke et al. (2011) UK J Older Peoples Nurs	Literature review relating to the provision of dementia care information.	n/a	Themes: -giving and receiving information -social disability
Conde-Sala et al. (2010) Spain Dement Geriatr Cogn Disord.	To identify the differential variables in perceived quality of life between patients and caregivers (spouse and adult child).	Cross-sectional analytic study N=251 patients and caregivers. N=112 spouse N=139 adult child	Negative perception of caregiving undertaken by adult children associated with greater caregiver burden Spousal caregivers hold a more positive perception.

Author(s) / Year / Country of study, Journal Source: *(abbrv. given)*	**Study design/aim**	**Sample characteristics of participants**	**Main themes/findings**
Davis (2011) Canada Dementia	A mixed-method research design to explore the experiential '*journey*' of living with Alzheimer's disease by caregivers.	Convenience sample: n=2 male caregivers (68-83 years) n=2 female caregivers (65-80 years). Marriage range = 44-60 years	Four themes identified: -Partnership, reciprocity -Resilience & forgiveness. -Dementia seen as a collaborative venture -A journey into the unknown.
de Witt et al. (2010) Canada J Adv Nurs	A hermeneutic study to gain a deeper understanding of the spatial interpretation of living alone experienced by older people with mild-moderate dementia.	n=8 female Age: 58-86 years who were widowed, divorced or separated.	Thematic findings: Living on the threshold –Being closed in (within their own homes) -Being there (the future) -Being out (everyday activities) -Keeping out (perceived threats to avoid from the outside world).
Dickinson et al. (2013) UK Int. Psychogeriat.	A qualitative study utilising a semi-structured interview format with people living with mild to moderate dementia. Aim: to investigate their views relating to Advance care planning.	n=17 people with mid-moderate dementia (age range 46-93 years) n=29 family caregivers (age range 44-89). Spousal or adult child caregivers – details not specified.	Practice implications: Health and social care professionals can build on people's preferences by informal planning, appropriate information and discussion of possible options.
Doherty et al. (2009) UK Dementia *[included in the review period 2016-2017]*	A qualitative study mapping the dementia care journey and the involvement and development of dementia care pathways within the East Midlands.	n=2 denoted as: n=1 Mr A being cared for by his daughter n=1 Mrs B being cared for by a close relative. Further details not specified.	Action points: -Provision of key worker for family -Information available to both patient and caregiver -Flexible transport planning -Provision of information (legal aspects) -Issues for families within BME communities not being addressed.

Author(s) / Year / Country of study, Journal Source: ***(abbrv. given)***	**Study design/aim**	**Sample characteristics of participants**	**Main themes/findings**
Dowling et al. (2014) US Alz Disease & Assoc Disorders	A randomised pilot study involving 5-weekly, one-on-one skill-building and mindfulness intervention sessions with family caregivers of people living with frontotemporal dementia. Aim: to assess positive and negative effects of intervention in relation to stress.	n=24 participants. n=female, n=7 male. All were spousal caregivers. Age range 48-74 years. Length of time as caregiver one-10 years. Ethnicity was white (90%), with a combined Hispanic and African American (10%).	Measures evaluated Pre-intervention: -caregiver burden -caregiver stress/distress -depressive mood On-going evaluation: -positive reappraisal -positive effects of well-being -personal strengths and attainable goal Post-intervention -increase of self-care.
Ducharme et al. (2011) Canada Gerontol.	A study to test the efficacy of a psychoeducational programme to aid the facilitation of caregivers in undertaking their role post dementia diagnosis of a family member.	Experimental group (n=62 EG) receiving the psychoeducational individual programme. 79% female. Mean age 60.37. Kinship to cared-for relative: 25.8% wife, 9.7% husband, 45.2% daughter, 8.1 son and 11.3 other. Control group (n=49 CG) receiving usual care.	Results indicated that post-programme members of the EG were more confident in dealing with caregiving situations and forward planning. In addition awareness of available services and coping strategies indicated.
Ducharme et al. (2012) Canada Home Health Care Service Quar.	A longitudinal study applying a grounded theory approach. Aim: to develop a model of the decision-making process of family caregivers and the placement of cognitively impaired relative within long term care.	n=18 participants, n=3 male, n=15 female. Kinship to older relative: n=4 spouse, n=11 child and n=3 (other relative – daughter-in-law or sibling). Mean age 61.4. Participants interviewed at 6 monthly intervals over an 18 month period within their own homes.	Decision-making process regarding placement of a cared-for relative was: -complex (requiring multiple contextual factors) -a process involving network interactions with formal (service providers) and informal (family and friends).
Ducharme et al. (2013) J Alz Dis Other Dement	A qualitative study (semi-structured interviews) to document the lived experience of spousal caregivers of younger people living with dementia.	n=12 participants. n=8 female (average age X=52 years) and n=4 male (average age X=60 years. Caring for spousal partner for 4= years with Alzheimer's diagnosis (9 out of 12) and mixed dementia (remaining 3).	Emergent themes: -managing behaviour -long quest for diagnosis and -nondisclosure to others -grief for loss of spouse -juggling unexpected roles and planning for the future.

Author(s) / Year / Country of study, Journal Source: *(abbrv. given)*	**Study design/aim**	**Sample characteristics of participants**	**Main themes/findings**
Exley et al. (2009) UK Dementia	Notification and discussion of a series of interrelated studies (NE of England) to explore the area of Advance Care Planning (ACP). Ultimate aim to produce guidance on ACP for people living with dementia and health care professionals.	N/A	N/A
Featherstonhaugh et al. (2017) Australia Dementia	Qualitative study involving face-to-face/ telephone interviews to explore the surrogate decision making of family caregivers	n=34 participants n= 5 spousal partners n= 29 children/child-in-law (majority female – details not specified).	Five themes relating to decision making: -Being -Growing into the role -Dealing with stress -Challenging healthcare professionals -Support from family members.
Gillies (2011) UK Dementia	Qualitative study. Face-to-face interviews with family caregivers to explore their subjective experiences of caring for a family member.	n=20 participants n=15 spousal (5 husbands and 10 wives) n=4 adult daughters and one adult son, all co-resident with their relative.	Experiences of caregivers providing insight into the relationships and the complexities of maintaining their relationships within the ambiguous dementia caregiving journey.
Hellström & Torres (2013) Sweden Aging Ment Health	A study based on 40 qualitative interviews undertaken with people with dementia and their spousal caregivers. To explore the disclosure preferences of cohabiting couples.	Participants n=40 n=20 people with dementia n=9 female, n=11 male. Age range 59-85 years. n=20 spousal caregivers. n=11 female, n=9 male. Age range not specified.	Analysis of data revealed five preference patterns: -want to know and tell (minus reservations) - want to know and tell (with reservations) -want to know but do not want to tell -want to know (undecided to tell) -cannot agree on either knowing or telling.

Author(s) / Year / Country of study, Journal Source: *(abbrv. given*	**Study design/aim**	**Sample characteristics of participants**	**Main themes/findings**
Hellström & Torres (2016) Sweden Dementia	A qualitative study to explore how the future is understood by couples living with dementia.	n=40 participants n=20 people with a diagnosis of dementia (age 59-85) n=20 spousal caregivers (age range not specified).	Critical periods and "*not yet horizons*" within the dementia journey. Themes relating to the future as being: -negative (expressed by n=3 couples) -couples disagreeing (seeing it as either positive or negative) -couple disagreeing seeing it as wholly negative (person with dementia) or not worthy of discussion (family caregivers and vice versa) -couple's perception of the future as being unknown.
Hennings et al. (2013) UK Palliat Med	Longitudinal narrative study, with 3 sequential interviews and diary accounts. To explore the experiences of married caregivers with their spousal partner residing in residential care.	n=27 (7 female & 3 male) recruited from 2 nursing homes. Further details not specified.	The experience of spousal caregivers is "*living within two worlds*". Recommendation: Nursing staff need to acknowledge the needs of spousal carers.
Hughes et al. (2010) UK Eur J Palliat Care	This article looks at the task of improving palliative care services to patients with dementia in North Tyneside.	n/a	Recommendations -ACP - psychological support - management of acute events and terminal care.
Kim et al., (2012) US J Adv Nurs.	A study utilising secondary data analysis of telephone surveys. Aim: to examine the multidimensional predictors of caregiver burden.	Interview information collated from surveys by the National Alliance for Caregiving, American Association of Retired Persons (2004). Sample of this study included n=302 caregivers. n= 172 female. n=130 male. Mean age: 47.06.	Findings: -Caregivers experience a moderate level of caregiver burden and spent more -number of hours of caregiving, -co-resident status of cared-for person -gender of caregiver.

Author(s) / Year / Country of study, Journal Source: ***(abbrv. given)***	**Study design/aim**	**Sample characteristics of participants**	**Main themes/findings**
Kjāllman et al. (2013) Sweden J Qual Stud Health & Wellbeing	To explore what it means to be an adult child of a person with dementia. Narrative interviews analysed using phenomenological hermeneutics	Open interviews with n=9 participants. n=8 female and 1=male. Age range: 35-65. Further details not specified.	Emergent major themes expressed by participants: -Burden of responsibility -Deep sense of grief and loss -Experience of psychic crisis and that they too may inherit the disease. -Adult child caregivers require substantial support to adapt to the loss a parent who is still alive.
Lee et al. (2015) Intern. BMC Palliat Care	Semi-structured face-to-face/telephone interviews – thematic analysis. Aim of study to determine expert views on key factors of good end of life care.	n=30 experts within the field of dementia care and or palliative care.	Four interconnected factors: -Leadership and management -Intervention and continuity of care
Lin et al. (2011) UK Dementia	Longitudinal grounded theory approach involving in-depth interviews. To explore carers' autonomy and health over a period of 18 months.	n=6 co-habiting couples. n=3 female and n=3 male. Age range of the person with dementia 64-77 and caregiver 64-72.	Four categories: -My life changed -Commitment -Responsibility and duty -Support. Adaptions varied between study participants.
Litherland & Robson (2014) UK Dementia Care	A qualitative report on a pilot study involving twelve people with dementia and eight family caregivers who attended 2.5 hour mindfulness intervention sessions over an eight week period.	Breakdown of participant data not stated.	Outcomes: -Impact of QoL -Reduction in anxiety -Improved sense of self -Improved pain control

Author(s) / Year / Country of study, Journal Source: ***(abbrv. given)***	**Study design/aim**	**Sample characteristics of participants**	**Main themes/findings**
Lloyd et al. (2016) UK Dementia	A literature review to explore family caregivers' experiences of positive aspects of caregiving (PAC).	n=14 quantative and qualitative studies (2000-2013) reviewed which met the aim of describing the multiple positive dimensions of caregiving.	Studies reported that PAC were achieved by: -Choices and adaptive strategies (qualitative studies) Research which warranted further investigation: -relating to experience of male caregivers -quantative research requiring a clear definition of the key concepts of PAC.
Miesen (2010) Netherlands Dementia	Exploring the context of a life-long attachment of people living with dementia. Aim: the development of a taught psychogeriatric module of study for healthcare professionals.	N/A	Proposed '*building blocks'* for a caregiving curriculum, to enable professional and practical ways of supporting people living with dementia.
O'Shaughness et al. (2010) UK J of Soc Res & Pract	An IPA analysis of semi-structured interviews undertaken with spousal caregivers of people with dementia. To explore the significant losses experienced within the marital relationship.	n=7 spousal caregivers n=2 female and n=2 husbands. Age range of participants 59-86 years. Length of time married 27-59 years. Diagnosis: n=5 people with dementia, one person living with Lewy Body related dementia. One diagnosis not specified.	Four overarching themes relating to both caregiver and cared-for person: -Connectedness and separateness -Tensions between required needs -Unknown future -Control/strategies
Peacock et al. (2014) Canada Palliat Supportive Care	A qualitative study to explore the vital role of family caregivers in the provision of end-of-life care to their relative. IPA methodological approach.	Two or three In-depth interviews undertaken over a period of one year, involving: n=4 wives, n=3 husbands, n=3 daughters and n=1 son. Spouses' ages ranged from 65-89 years. Adult children ages ranged from 49-63 years.	Two essential aspects of end-of-life dementia caregiving: -Being-with -Being-there An understanding of bereaved caregivers' perspectives will assist healthcare practitioners in being able to offer empathic support.

Author(s) / Year / Country of study, Journal Source: *(abbrv. given)*	**Study design/aim**	**Sample characteristics of participants**	**Main themes/findings**
Peacock et al. (2014) Canada BMC Nurs	Open-ended qualitative (phenomenological) study relating to the experiences of caregivers from dementia diagnosis to final bereavement.	Purposive sample of n=11participants in total. n=4 wives, 3 husbands, 3 adult daughters and one adult son. Each having provided an average of 6 years of caregiving to their family member. Age range for spousal partners: 65-89, children: 49-63 years.	Caregiving themes relating to: -Getting a diagnosis -Managing at home -Transition to long-term care -End of life. Additional sub-themes reflected a continuous grieving process.
Peacock et al. (2016) Canada Dementia	A qualitative study exploring anticipated loss and previous multiple losses experienced by spousal caregivers..	n=10, 9 female and one male. Interviewed twice within participants own home over a period of two weeks. Diagnosis of dementia – various.	The process of the reclaiming of self by participants in response to loss and bereavement.
Peel & Harding (2014) UK Dementia	Focus on British carers' talk about health and social care services. To explore data from a mixed-method format of research.	Multi-method online and paper questionnaire (n=185) with 85% female. Four focus groups (n=15) and eleven semi-structured in-depth interviews with people with dementia and caregivers.	Themes reported: -Services as a 'maze' -Services limited -The battle and fighting discourse deployed by carers. Carers find navigating systemic issues in dementia care time-consuming and often more difficult than the caregiving.
Piiparinen & Whitlatch (2011) Canada Dementia	A conceptual discussion as to the existential loss to well-being experienced within the caregiving dyad	N/A	Findings reported: Family caregivers' actions of avoidance or acceptance of loss influencing behavioural interaction within the caregiving dyad.
Purves (2010) Canada Dementia	2-stage qualitative process: in-depth open-ended interviews (6 weeks) and the analysis of audio/video family conversations (6 months).To explore how caregivers position themselves in carrying out their role.	n=5 one couple (husband as caregiver and wife diagnosed with dementia) supported by three adult children): Ethnicity: Japanese Canadian.	The importance of: interactions within the family network which indicated generational /cultural differences2.0, as well as the family's collective effort in maintaining the competencies of their family member.

Author(s) / Year / Country of study, Journal Source: ***(abbrv. given)***	**Study design/aim**	**Sample characteristics of participants**	**Main themes/findings**
Richardson (2010) US Omega	Mixed-methods study, including face-to-face interviews to explore widowers' experiences post bereavement and current social support.	n=200 widowers 12 -22 months post bereavement. Age range: 58-91 years. Mean 75 years. Ethnicity: 82% Caucasian, 18% African-American.	Older bereaved male caregivers demonstrated less positive effects and the development of complicated grief. Restoration-oriented coping – socialising assisted in positive feelings of extensive caregiving.
Sami & Manthorpe (2011) UK Heal and Soc Care	A qualitative study to explore experiences, opinions and attitudes of older adults living in the community regarding planning for their future in context of the Mental Capacity Act (MCA).	Structured interviews with n=31 participants involved with various community-based services. Further details of participants not specified.	Four main themes: -Individual inclination to plan -Types of plans -Reasons for planning or not planning -Support with planning. Recommendation: MCA to be discussed at an earlier stage with older people.
Shanley et al. (2011) Australia Dementia	In-depth qualitative interviews exploring the experiences and needs of family caregivers at the end-stage of dementia.	N-15 N=10 spousal caregivers (5 male/5 female) Age range 43-75 years N=5 adult children providing to a parent (2 sons/3 daughters). Age range 35-58 years.	Study provided a more personalised account of caregiving. Carers expressed a range of instrumental and psychosocial needs with regard to: -Being a carer -Seeking support -Witnessing a loved one *"fade away"* -Re-establishing life post bereavement
Skaalvik et al. (2016) Norway Dementia	A qualitative study to explore how the relatives of people with Alzheimer's disease expressed Self 2 and Self 3 according to Harré's social constructionist theory of selfhood.	n-20 (n=2 members of 10 families caring for a family member). The composition of the sample was heterogeneous and included wives, husbands, daughters, sons and in-laws.	Findings reported with regard to participants' sense of self highlighted that Alzheimer's disease challenged their -Personal attributes -Relationships and positioning.

Author(s) / Year / Country of study, Journal Source: ***(abbrv. given)***	**Study design/aim**	**Sample characteristics of participants**	**Main themes/findings**
Stokes et al. (2014) UK Dementia	Semi-structured interviews with spousal caregivers to elicit participants' understanding of dementia. IPA analysis of data.	n=10 (6 female /4 male). All at differential stages of their caregiving experience. (No further participant details given by the authors).	Four broad themes emerged: -Lack of information -Personal understanding and implications for adjustment -Societal understanding and stigma -Lack of partnership working
Sutcliffe et al. (2016) UK Dementia	An exploration of the topics relating to service delivery undertaken with staff in two community mental health teams.	Convenience sample n=23 staff members from two NHS Mental Health Trust in the NW of England. Recruited to take part in one, one hour focus group discussions.	Reported findings suggested by staff for improvement included: -Flexible services -Dementia training for staff -Quality care in acute hospital settings.
Van der Steen et al. (2013) Europe Palliat. Med.	Five-round Delphi study. Based on literature, a core group of 12 experts from 6 countries drafted a set of core domains with salient recommendations for each domain	A total of 64 (72%) experts from 23 countries evaluated a set of 11 domains and 57 recommendations.	Provision of the first definition of palliative care in dementia based on evidence and consensus. In addition a framework to provide guidance for clinical practice, policy and research
Van der Steen et al. (2016) Europe Int. Psychogeriat	To examine in detail the revision of the applicability of palliative care in dementia.	the opinions of the international panel of 64 experts around the applicability of palliative care, we explored feedback they provided in the Delphi process (2014)	Concerns about bringing up end-of-life issues prematurely and the relabelling of dementia care as palliative care. Researchers suggested that further studies required.
Zimmerman (2013). J Med. Humanities	Article exploring the experiential accounts of adult children caring for a parent.	Review of the published and autobiographical writing of the experiences of two adult caregiving children	A conceptualisation of illness narratives and the influence of the caregivers' physical and emotional stability.

Appendix 2.0: Letter and Information for Alzheimer's Society Branch Colleagues

The Journey from Dementia Diagnosis to Final Bereavement:
An Exploration of Anticipatory Grief, Loss and Bereavement Experienced by Family Caregivers of People with Dementia

Dear <**name of Alzheimer's Society colleague** >

As per our telephone conversation, I am inviting family caregivers of people with dementia to take part in my PhD research study and as previously discussed I would like you to be the initial contact with potential participants. Before you decide to approach caregivers it is important for you to understand why the research is being carried out and what it will involve. Please take time to read the following information carefully, which hopefully will answer any questions you may have regarding the recruitment of participants. Please don't hesitate to contact me if you would like to have more information.

What is the study about?

Family caregivers of some with dementia assume their caring role for a variety of reasons. They become carers because of love, a sense of commitment and duty to their family, partner or friend. Yet caring for someone with dementia is about more than memory loss, there are many 'losses' involved. The aim of this research is to explore, in part retrospectively, the complex emotional experiences of thirty caregivers in relation to change, loss and adjustment, to elucidate a deeper understanding of the lived experience, the perceived and understood reality of the experiential journey of caregivers.

Why have you been asked?

You are in a unique position of knowing the carers who are involved with your branch and who would be emotionally at ease with being interviewed in relation to their caring role.

What are you being asked to do?

You are being asked to make the initial approach to:

a. **Five** family caregivers who have previously cared for a person with dementia (who is now deceased) and who are willing to take part in Group One of this research study.

b. **Two** family carers who are currently caring for a person with advanced dementia, (whether they are a family member or friend and are living at home or in permanent residential care). These participants will take part Group Two of this research study.

How will participants become involved in the study?

After your initial contact, please give each interested carer/participant a research study pack which includes an introductory letter and the leaflets *'Your Journey as a Caregiver'* and *'Information for Participants'* applicable to either Group One or Group Two (sealed information packs are included herewith). For those carers who are willing to participate, they have been requested to return the completed section *'Consent to Contact'* to me and I will then contact them directly by telephone to arrange interview dates and times, as well as answering any questions that they may have concerning the research.

How will the study be carried out?

Each carer-participant will be asked to take part in an informal interview(s) with me, lasting for the duration of one hour. These interviews will be recorded and they will be asked to tell me their experiences of: "*your journey*." Please note that further time will be allocated before and after the interview(s) if they would like to discuss anything in relation to the study.

The study is divided into two groups:

Group One: Participants who have previously cared for a person with dementia and who have experienced the first anniversary of their bereavement. They should also have experienced the loss of their loved one within the last five years. The participants involved with this group will take part in a single one hour interview.

Group Two: Participants who are currently caring with someone with advanced dementia. The person with dementia may be residing at home or with a residential care environment. The care-participants involved with this group will take part in three one hour interviews over an extended period lasting no more than eighteen months.

What happens if a participant wishes to withdraw from the study?

I am appreciative that the research subject could be extremely emotive for some people and would therefore like to stress that participants will be assured that they can withdraw from the study at any time, even during the interview stage. If they choose to withdraw they will not be contacted be me again with regard to this research study.

What will happen to the information that is gathered?

The information will be used to identify ways of meeting the emotional and psychological needs of carers of people with dementia, as well as considering the development of the future service provision of information, education and training for caregivers of people with dementia

The names of participants, their family members or branch staff will be anonymised in the thesis or any other documentation relating to this research study. All participants and branches of the Alzheimer's Society involved with the research will receive a summary of the thesis if they so wish.

What happens if I need to contact you?

You can either write to Jo Alexjuk, Northumbria University, c/o Room 007, Coach Lane Campus East, Coach Lane, Newcastle upon Tyne, NE7 7XA or contact me on: 0779 650 1009.

Thank you again for your assistance.

Best wishes

Jo Alexjuk

Appendix 3.0: Information for Group One Participants (PG1)

3.1 Letter of Introduction

Your Journey as a Caregiver

<Name and address of carer-participant>

Jo Alexjuk
PhD Research Student
Northumbria University,
c/o Room 007, Coach Lane Campus
East, Coach Lane, Newcastle upon
Tyne, NE7 7XA

Tel: 0779 650 1009

Ref: Group One

Date: <Date as postmark>

Dear <Name of carer-participant>
Re: Research to Explore Your Journey as a Caregiver.
Thank you for agreeing to take part in my PhD research study. As previously discussed with <**name of Alzheimer's Society colleague/branch>** the aim of this research is to explore '*your journey'* as a caregiver. Please read the enclosed leaflets '*Your Journey as a Caregiver'* and *'Information for Participants'*. On receipt of the consent to contact form I shall telephone you to make arrangements for the date, time and location of our first interview. If you have any queries regarding the research please do not hesitate to contact me on: 0779 650 009.

Thank you again for your participation.

Yours faithfully,

Jo Alexjuk
PhD Research Student

Encs.

3.2 Information Leaflet

What happens if you do not wish to take part?

Please be assured that you have the right not to take part in this research and that you will not be contacted again regarding this research if you do not wish to be a participant.

What will happen to the Information that is gathered?

The information will be used to elicit a greater understanding of the emotional and psychological needs of family caregivers of people with dementia. As well as recommendations for the development of future service provision for family caregivers of people with dementia.

Will your name appear in the information?

No participant will be named in the thesis or any other documentation relating to this research.

All participants involved with the research will receive a summary of the report if they so wish.

What do you do if you wish to become a participant?

Please read, complete and return the consent form, which can be found as a tear-off section in the **Your Journey as a Carer** leaflet. A s.a.e. has been provided

Thank You

<Label with the name of the family support worker, address and telephone number of local branch>

Information for Carer-Participants

Group One

Questions you may have about the research study

Who is undertaking the research and why?

Hello, my name is Eva Joanna Alexjuk (Jo).
I am currently a PhD research student within the School of Community, Health and Educational Studies at Northumbria University.
I am undertaking this research for my PhD thesis and it is **not** a part of my role with the Alzheimer's Society.
I have worked for the Alzheimer's Society North Tyneside Branch for over eleven years, as well as voluntary work for nine years in the roles of bereavement volunteer and chair with Cruse Bereavement Care Tyneside.

What is the study about?

Family caregivers, like yourself, become carers because of love, a sense of commitment and duty to their family, partner or friend. Yet caring for someone with dementia is about more than memory loss, there are many '*losses*' involved.

The aim of this study is to explore the complex and emotional experiences of caregivers, such as yourself, who previously cared for a loved one with dementia. To hopefully gain a better understanding of the experiences of family caregivers and to identify ways of meeting the emotional requirements of caregivers in the future.

Why have you been asked?

Because you have previously undertaken the role of caregiver of a person with dementia you are in a position to help me understand some of the experiences of caring for a family member.

What are you being asked to do?

You are being asked to take part in an informal and recorded interview with me.

The interview will last for approximately one hour in which I shall ask you to tell me the experiences of '*your journey*'.

Please note that time will be allocated before and after each interview if you would like to discuss anything in relation to this study

3.3 Your Journey as a Caregiver and Consent to Contact Form

Group One

Consent to contact form

in relation to research regarding my journey as a caregiver of a person with dementia

Name of participant ..... I ..... (participant)

Address of participant ..... understand the information presented to me and agree to being contacted to take part in this study

..... (participant)

Post code ..... Signature .....

Telephone ..... Date .....

Name of the person with dementia .....

Relationship of the person with dementia to the participant .....

Return in the s.a.e. provided to: Jo Alexjuk, Northumbria University, c/o Room 007, Coach Lane Campus East, Coach Lane, Newcastle upon Tyne, NE7 7XA Tel: 0779 650 1009

CARER SUPPORT

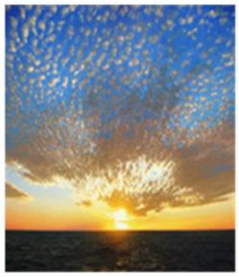
If you require further support please contact the family support worker at your local branch of the Alzheimer's Society (name and address are given below).

Carers can also meet together with other caregivers to discuss the many aspects of caring in a relaxed and informal setting, at one of the support group meetings or Alzheimer's cafés facilitated by your local branch.

If you would like to attend any of these meetings, or simply need someone to talk to regarding these events please contact a the member of staff at the address below.

<Label with the name of the family support worker, address and telephone number of local branch>

Your Journey as a Caregiver



Group One

Retracing your journey

The route undertaken during a caregiver's journey will always be individual to each person,

Caring for someone with dementia is about more than their just memory loss. There are many 'losses' involved.

The aim of this research is to retrace your journey.

To explore the experiences you have had during your journey whilst caring for someone with dementia.

During our recorded interview, lasting for approximately one hour, we will explore your experiences of caring for your loved one.

Time will also be allocated before and after the interview if you would like to discuss anything in relation to this research study.

On receipt of your consent to contact slip I will contact you to discuss the study and will then confirm by post an agreed time, date and place for Interview.

Please note that the location of the interview can be undertaken at your local Alzheimer's Society branch, or at Northumbria University, or if you prefer within your own home.

Please be assured that:

- You can withdraw from the research at any time and you will not be contact again with regard to this research if you choose not to be involved.
- You will not be personally named as anonymity and confidentiality will be strictly undertaken.
- The storage of data will be within a secure setting for digitally recorded and transcribed material.
- The transcription and analysis of data will be undertaken by myself and will be wiped or shredded after a period of ten years.
- You will receive a summary of the final thesis if you so wish.
- If you require further emotional support you will be referred to your local Alzheimer's Society carers support group or your own GP

Please note that this research is being carried out in relation to my status as a PhD research student of the School of Community, Health and Educational Studies at Northumbria University and not as part of my role as a Trainer with the Alzheimer's Society North Tyneside Branch

Thank You

Declaration of consent to contact

I have read and understand the purpose of the study

I have had the chance to ask questions about the study and these have been answered to my satisfaction

I am willing to be contacted to be interviewed and happy for my comments to be tape-recorded

I understand that I can withdraw at any time if I change my mind and this will not affect my relationship with the Alzheimer's Society Branch or members of staff

I know that my name and details will be kept confidential and will not appear in any printed documents

3.4 Interview Confirmation Letter

Your Journey as a Caregiver

<Name and address of carer-participant>

Jo Alexjuk
PhD Research Student
Northumbria University,
c/o Room 007, Coach Lane Campus
East, Coach Lane, Newcastle upon
Tyne, NE7 7XA Tel: 0779 650 1009

Ref: Group One

Date: <Date as postmark>

Dear <Name of carer-participant>
Re: Research to Explore Your Journey as a Caregiver

Thank you for agreeing to take part in my PhD research study. As agreed I wish to confirm our initial interview details as being:

Time:

Date:

Location:

If you have any queries regarding the research please do not hesitate to contact on: 0779 650 1009. Thank you again for your participation and I look forward to meeting you.

Yours faithfully,

Jo Alexjuk
PhD Research Student

3.5 Declaration of Consent to Collect Data

Your Journey as a Caregiver

Declaration of consent

to collect data

Please read the following:

- I have read the information provided relating to this research study and understand the purpose of the study.
- I have had the chance to ask questions about the study and these have been answered to my satisfaction.
- I am happy for my comments to be audio-recorded.
- I understand that the recording of this interview can be paused or stopped at any time.
- I understand that I can withdraw completely at any time if I change my mind and this will not affect my relationship with the Alzheimer's Society Branch or members of staff.
- I know that my name and details will be kept confidential and will not appear in any printed documents.

Signature of carer-participant..... Date.....

Signature of researcher..... Date.....

Appendix 4.0: Information for Group Two Participants (PG2)

4.1 Letter of Introduction

Your Journey as a Caregiver

<Name and address of carer-participant>

Jo Alexjuk
PhD Research Student
Northumbria University,
c/o Room 007, Coach Lane
Campus East, Coach Lane,
Newcastle upon Tyne, NE7
7XATel: 0779 650 1009

Ref: Group Two

Date: <Date as postmark>

Dear <Name of carer-participant>

Re: Research to Explore Your Journey as a Caregiver.

Thank you for agreeing to take part in my PhD research study. As previously discussed with <**name of Alzheimer's Society colleague/branch>** the aim of this research is to explore '*your journey'* as a caregiver. Please read the enclosed leaflets '*Your Journey as a Caregiver'* and *'Information for Participants'*. On receipt of the consent to contact form I shall telephone you to make arrangements for the date, time and location of our first interview. If you have any queries regarding the research please do not hesitate to contact me on: 0779 650 009.

Thank you again for your participation.

Yours faithfully,

Jo Alexjuk
PhD Research Student

Encs.

4.2 Information Leaflet for Participants

What happens if you do not wish to take part?

Please be assured that you have the right not to take part in this research and that you will not be contacted again regarding this research if you do not wish to be a participant.

What will happen to the Information that is gathered?

The information will be used to elicit a greater understanding of the emotional and psychological needs of family caregivers of people with dementia. As well as recommendations for the development of future service provision for family caregivers of people with dementia.

Will your name appear in the information?

No participant will be named in the thesis or any other documentation relating to this research.

All participants involved with the research will receive a summary of the report if they so wish.

What do you do if you wish to become a participant?

Please read, complete and return the consent form, which can be found as a tear-off section in the **Your Journey as a Carer** leaflet. A s.a.e. has been provided

Thank You

<Label with the name of the family support worker, address and telephone number of local branch>

Information for Carer-Participants

Group Two

Questions you may have about the research study

Who is undertaking the research and why?

Hello, my name is Eva Joanna Alexjuk (Jo).
I am currently a PhD research student within the School of Community, Health and Educational Studies at Northumbria University.
I am undertaking this research for my PhD thesis and it is **not** a part of my role with the Alzheimer's Society.
I have worked for the Alzheimer's Society North Tyneside Branch for over eleven years, as well as voluntary work for nine years in the roles of bereavement volunteer and chair with Cruse Bereavement Care Tyneside.

What is the study about?

Family caregivers, like yourself, become carers because of love, a sense of commitment and duty to their family, partner or friend. Yet caring for someone with dementia is about more than memory loss, there are many '*losses*' involved.

The aim of this study is to explore the complex and emotional experiences of caregivers such as yourself, who are currently caring for a family member with advanced stage related dementia. To hopefully gain a better understanding of the experiences of family caregivers and to identify ways of meeting the emotional requirements of caregivers in the future

Why have you been asked?

Because you are a caregiver of a person with advanced dementia you are in a position to help me understand some of the experiences of caring for a family member.

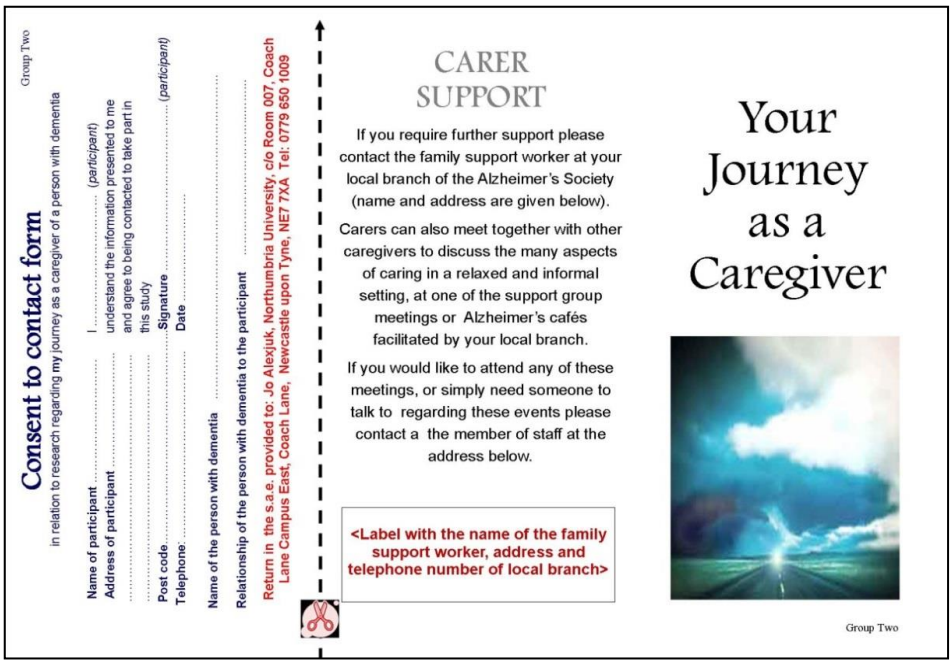
What are you being asked to do?

During the course of 18 months you will be asked to take part in three separately recorded informal interviews with me.

Each interview will last for approximately one hour in which I shall ask you to tell me the experiences of '*your journey*'.

Please note that time will be allocated before and after each interview if you would like to discuss anything in relation to this study

4.3 Your Journey as a Caregiver Leaflet for Participants



Group Two

Consent to contact form

in relation to research regarding my journey as a caregiver of a person with dementia

Name of participant ..... I ..... *(participant)*

Address of participant ..... understand the information presented to me and agree to being contacted to take part in this study

..... **Signature** ..... *(participant)*

Post code ..... **Date** .....

Telephone .....

Name of the person with dementia .....

Relationship of the person with dementia to the participant .....

Return in the s.a.e. provided to: Jo Alexjuk, Northumbria University, c/o Room 007, Coach Lane Campus East, Coach Lane, Newcastle upon Tyne, NE7 7XA Tel: 0779 650 1009

CARER SUPPORT

If you require further support please contact the family support worker at your local branch of the Alzheimer's Society (name and address are given below).

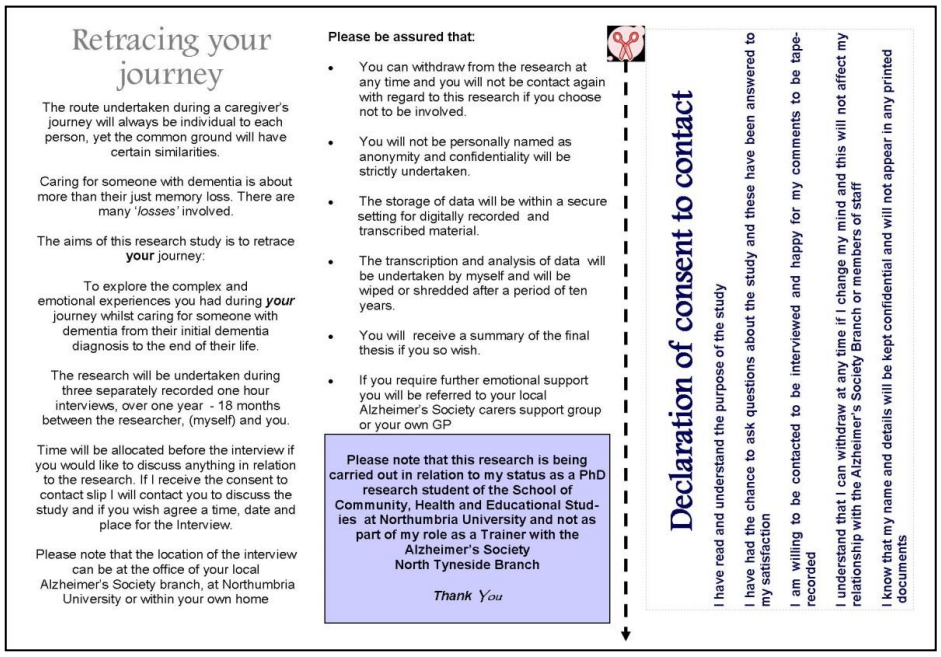
Carers can also meet together with other caregivers to discuss the many aspects of caring in a relaxed and informal setting, at one of the support group meetings or Alzheimer's cafés facilitated by your local branch.

If you would like to attend any of these meetings, or simply need someone to talk to regarding these events please contact a the member of staff at the address below.

<Label with the name of the family support worker, address and telephone number of local branch>

Your Journey as a Caregiver

Group Two



Retracing your journey

The route undertaken during a caregiver's journey will always be individual to each person, yet the common ground will have certain similarities.

Caring for someone with dementia is about more than their just memory loss. There are many '*losses*' involved.

The aims of this research study is to retrace **your** journey:

To explore the complex and emotional experiences you had during ***your*** journey whilst caring for someone with dementia from their initial dementia diagnosis to the end of their life.

The research will be undertaken during three separately recorded one hour interviews, over one year - 18 months between the researcher, (myself) and you.

Time will be allocated before the interview if you would like to discuss anything in relation to the research. If I receive the consent to contact slip I will contact you to discuss the study and if you wish agree a time, date and place for the Interview.

Please note that the location of the interview can be at the office of your local Alzheimer's Society branch, at Northumbria University or within your own home

Please be assured that:

- You can withdraw from the research at any time and you will not be contact again with regard to this research if you choose not to be involved.
- You will not be personally named as anonymity and confidentiality will be strictly undertaken.
- The storage of data will be within a secure setting for digitally recorded and transcribed material.
- The transcription and analysis of data will be undertaken by myself and will be wiped or shredded after a period of ten years.
- You will receive a summary of the final thesis if you so wish.
- If you require further emotional support you will be referred to your local Alzheimer's Society carers support group or your own GP

Please note that this research is being carried out in relation to my status as a PhD research student of the School of Community, Health and Educational Studies at Northumbria University and not as part of my role as a Trainer with the Alzheimer's Society North Tyneside Branch

Thank You

Declaration of consent to contact

I have read and understand the purpose of the study

I have had the chance to ask questions about the study and these have been answered to my satisfaction

I am willing to be contacted to be interviewed and happy for my comments to be tape-recorded

I understand that I can withdraw at any time if I change my mind and this will not affect my relationship with the Alzheimer's Society Branch or members of staff

I know that my name and details will be kept confidential and will not appear in any printed documents

4.4 Interview Confirmation Letter

Your Journey as a Caregiver

<Name and address of carer-participant>

Jo Alexjuk
PhD Research Student
Northumbria University,
c/o Room 007, Coach Lane Campus
East, Coach Lane,
Newcastle upon Tyne,
NE7 7XA
Tel: 0779 650 1009

Ref: Group Two

Date: <Date as postmark>

Dear <Name of carer-participant>

Re: Research to Explore Your Journey as a Caregiver

Thank you for agreeing to take part in my PhD research study. As agreed I wish to confirm our initial interview details as being:

Time:

Date:

Location:

If you have any queries regarding the research please do not hesitate to contact on 0779 650 1009. Thank you again for your participation and I look forward to meeting you.

Yours faithfully,

Jo Alexjuk
PhD Research Student

4.5 Declaration of Consent to Collect Data

Your Journey as a Caregiver

Declaration of consent to collect data

Please read the following:

- I have read the information provided relating to this research study and understand the purpose of the study.
- I have had the chance to ask questions about the study and these have been answered to my satisfaction.
- I am happy for my comments to be audio-recorded.
- I understand that the recording of this interview can be paused or stopped at any time.
- I understand that I can withdraw completely at any time if I change my mind and this will not affect my relationship with the Alzheimer's Society Branch or members of staff.
- I know that my name and details will be kept confidential and will not appear in any printed documents

Signature of participant ..... Date .....

Signature of researcher ..... Date .....

Appendix 5.0

Interview question/prompts

How did you *feel/cope* in relation to:

- receiving the dementia diagnosis
- your day-to-day life together
- the future
- your own health needs
- the health needs of *(the name of the person with dementia)*
- <*the name of the person with dementia*> entering/not entering permanent residential
- <*the name of the person with dementia*> at the end of their life

How did you respond to the situation and what support do/did you receive:

- when receiving the diagnosis
- during your day-to-day life
- to the changes in your own health needs
- to the changes in the health needs of *(the name of the person with dementia)*
- from members of the family, friends and health workers
- to accessing/not to accessing respite or day care
- when making the decision with regard to <*the name of the person with dementia*> entering not entering permanent residential care
- when <*the name of the person with dementia*> died (carer-participant group one)

What personally helps/helped you in your role as caregiver:

- when receiving the diagnosis
- during your day-to-day life
- with regard to your own health needs
- with regard to the change in the <*name of the person with dementia*> health needs
- to accessing/not to accessing respite or day care
- when making the decision with regard to the <*name of the person with dementia*> entering/not entering residential care
- when <*the name of the person with dementia*> died (carer-participant group one)
- what advice would you give other family caregivers who will undertake the dementia care giving journey in the future

Appendix 6.0: Research Poster